# Knowledge to Action: Addressing the social determinants of health to promote Aboriginal and Torres Strait Islander Social and Emotional Wellbeing

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# **Terminology**

Throughout this thesis Aboriginal and Torres Strait Islander is used when referring specifically to the Australian context and population as this is the preferred terminology expressed by Aboriginal and Torres Strait Islander communities.

The term Indigenous is used to refer globally to Indigenous or First Nations populations including Aboriginal and Torres Strait Islander populations.

## **Included Publications**

1. Brodie T, Pearson O, Cantley L, Cooper P, Westhead S, Brown A, Howard NJ. (2021) Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the Cultural Pathways Program. Prim Health Care Res Dev. 2021 Jun 29;22:e35. doi: 10.1017/S1463423621000402. PMID: 34184630; PMCID: PMC8278791

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# **List of Abbreviations**

| ACCHO Aboriginal Community Controlled Organisation  ACOSS Australian Council of Social Services  ADS Aboriginal Diabetes Study  AHCSA Aboriginal Health Council of South Australia  AHREC Aboriginal Health Research Ethics Committee  APC Admitted Patient Care  AIATSIS The Australian Institute of Aboriginal and Torres Strait Islander Studies  AIMhi Aboriginal and Islander Mental health initiative  CALHN Central Adelaide Local Health Network  Census Australian Population Census  COAG Council of Australian Governments  CPP Cultural Pathways Program  CREATE The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange  CSDH Commission for the Social Determinants of Health Performance Framework  ISBAR Identify, Situation, Background, Assessment and Recommendation mnemonic  KPI Key Performance Indicator  NAHSWP National Aboriginal Health Strategy Working Party  NALHN Northern Adelaide Local Health Network  NATSISS National Aboriginal and Torres Strait Islander Health Survey  NATSIHS National Aboriginal and Torres Strait Islander Health Survey  NGO Non-Government Organisation  NHMRC National Health and Medical Research Council  PHN Primary Health Network  Pt Participant/s  RAP Reconciliation Action Plan  REDCap Research Electronic Data Capture  SAHMRI South Australian Health Research Accord  WHO World Health Organisation                         |            |   |
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| SAHMRI South Australian Health and Medical Research Institute  SOAP Subjective, Objective, Assessment and Plan note  The Accord The South Australian Health Research Accord   | RAP        | Reconciliation Action Plan  |
| SOAP Subjective, Objective, Assessment and Plan note  The Accord The South Australian Health Research Accord  | REDCap     | Research Electronic Data Capture  |
| The Accord The South Australian Health Research Accord  | SAHMRI     | South Australian Health and Medical Research Institute                    |
|   | SOAP       | Subjective, Objective, Assessment and Plan note                           |
| WHO World Health Organisation   | The Accord | The South Australian Health Research Accord                               |
|   | WHO        | World Health Organisation   |

### **Abstract**

Aboriginal and Torres Strait Islander cultures are one of the oldest living cultures in the world with philosophies, knowledges and practices that sustained culture and people through great adversity. One of these philosophies is Aboriginal and Torres Strait Islander social and emotional wellbeing, which encapsulates the holistic view of life and underpins Aboriginal and Torres Strait Islander ways of knowing, being and doing. Social and emotional wellbeing represents the interconnection of spirituality, connection to Country, family, community, mind and emotions and the body, and how these are essential to health and wellbeing. Social and emotional wellbeing also recognises historical, political and social factors which shape and impact health and wellbeing of individuals and communities. Ongoing colonial violence has undoubtedly contributed to Aboriginal and Torres Strait Islander communities experiencing adverse outcomes on all health and social measures. Indigenous knowledge and self-determination are key to improving health and wellbeing outcomes, and in a colonial context it is necessary to bring together Indigenous and non-Indigenous knowledge at the interface to understand and inform health systems, policy and practice.

The social determinants of health, such as education, employment, housing and income, have proven complex in their contribution to health and social outcomes across the globe. Whilst many policies, plans, programs and initiatives have been implemented in an attempt to address unmet health and social needs, it has become increasingly evident that imposed solutions which are not self-determined are not the answer. Evidence-based understandings are necessary to implement holistic responses to social and emotional wellbeing addressing a range of cultural, historical, political, and social factors that shape health and wellbeing. This thesis outlines a PhD program of work which aimed to build foundational understandings on approaches to address social determinants of health and promote action on social and emotional wellbeing. An Indigenous methodology underpinned the mixed methods, iterative research design which included prioritising Indigenous ways of knowing, being and doing, insider approaches and Indigenous governance and leadership. Indigenous and non-Indigenous knowledges were integrated to describe community level outcomes for mental health and the social determinants of health. An enhanced scoping review methodology identified health programs addressing one or more social determinants. Practice-based evidence was generated from a developmental evaluation of an initiative addressing unmet social and cultural needs of Indigenous South Australians. Community-level outcomes emphasised significant unmet mental health and social needs for South Australian communities. Review findings highlight that few programs specifically addressed or provided coordinated action on the social determinants of health. A focus on emerging themes, complexity and reflective practice generated practice-based evidence for implementing strengths-based case management to identify unmet needs, engage in goal setting and broker connections with social and health services. This thesis outlines a range of innovative practice, methodological, and research considerations for promoting social and emotional wellbeing. Future initiatives need to consider system-level factors and measure the impact of holistic responses to expand the existing practice-based evidence that integrates the social determinants of health to promote social and emotional well-being.

**Declarations** 

I certify that this work contains no material which has been accepted for the award of any

other degree or diploma in my name in any university or other tertiary institution and, to

the best of my knowledge and belief, contains no material previously published or written

by another person, except where due reference has been made in the text. In addition, I

certify that no part of this work will, in the future, be used in a submission in my name

for any other degree or diploma in any university or other tertiary institution without the

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Australian Government Research Training Program Scholarship.

Tina Brodie

29 April 2023

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Kaiya and Kakirra, for inspiring me to make the world better for you and for all

Aboriginal and Torres Strait Islander children.

Tirritpa, for weathering the storm so the sun can shine for us. This would not have

happened without you. Ngaityalya.

Griffin, for being by far, the best PhD buddy.

My supervisors, Professor Alex Brown, Associate Professor Odette Pearson, and

Associate Professor Natasha Howard. Thank you for your unwavering support, guidance

and wisdom.

To all of the Mob who over the years have shared their knowledge, wisdom, time, stories

and self with me. For the yarns that have challenged and changed me. This work is for all

of you, and all of us.

Still here.

18

# **CHAPTER ONE:**

INDIGENOUS KNOWLEDGE AS THE KEY TO ACTION
ON THE SOCIAL DETERMINANTS OF HEALTH

19

"We know we cannot live in the past, but the past lives in us."

Charles Perkins (Wormleaton 2022)

### Indigenous Knowledge and Standpoint

As one of the oldest living cultures in the world, Aboriginal and Torres Strait Islander people have been sustained by stories and lived experiences shared across generations to shape worldviews, values and perspectives. This collective knowledge is often referred to as Indigenous knowledge. Aboriginal and Torres Strait Islander knowledge conceptualises health and wellbeing as holistic, and as part of these understandings, it is not possible to separate the cultural historical, political and social factors which shape health and wellbeing outcomes. As an Indigenous researcher, bringing myself, my Indigeneity, my reflections, insights and learnings to the research is part of the methodology. My lived experiences, who I am, where I come from and how I got here, have shaped the way I view the world and they give me a unique perspective. Consistent with this approach and cultural responsibilities, it is necessary to begin by both establishing myself through relationality as well as the standpoint, or framework, which informs and is informed by this research (Dickson 2020; Moreton-Robinson 2013).

I am an Aboriginal woman with connections to Yandruwandha and Yarrarawarrka. I was born on Wongatha Country (Kalgoorlie, Western Australia) where I lived for 20 years before I moved to Kaurna Country (Adelaide, South Australia) to go to university. I've been living and working on Kaurna Country for 17 years with my husband and my two children who are Adnyamathanha, Kaurna, Narungga, Ngarrindjeri and Wirangu. I have worked as a social worker in various project, clinical and leadership roles mostly with Aboriginal and Torres Strait Islander children and families. My relationship to Country and my identities as a mother, daughter, cousin, sister and member of the community are shaped by the broader socio-historical context which will be outlined in Chapter One. These identities and experiences are shared by many Aboriginal and Torres Strait Islander people to whom I am connected.

This chapter presents the journey of Aboriginal and Torres Strait Islander communities from the beginning, through invasion, to current experiences that are relevant for understanding the health, wellbeing and lived experiences of Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander cultures are explored including complex systems of spirituality, social organisation, language, and Country. The importance of spirituality is reiterated as the fundamental basis of these systems in order to provide an understanding of how all aspects of Aboriginal and Torres Strait Islander life are intrinsically related. Aboriginal and Torres Strait Islander history is explored as part of defining the context of this PhD program of work, particularly how racial theories, violence, and government policies have significantly shaped health and social outcomes experienced by the population. Whilst it is necessary to describe these adverse outcomes in some detail, the story told in this chapter is also one of resilience including Aboriginal and Torres Strait Islander knowledges, identity, diversity, activism and self-determination. This chapter introduces current understandings of Aboriginal and Torres Strait Islander social and emotional wellbeing and details the conceptualisation of the cultural historical, political and social determinants of health as key concepts underpinning this program of work.

### 1.1 Aboriginal and Torres Strait Islander holistic wellbeing

"Indigenous spirituality derives from a philosophy that establishes the holistic notion of the interconnectedness of the elements of the earth, and the universe...whereby people, the plants and animals, landforms and celestial bodies are interrelated."

### Grieves (2008) p.362

Aboriginal and Torres Strait Islander knowledge estimates first peoples thriving on this continent since time immemorial (Broome 2002; Edwards 2007) with 'Western science' estimating at least 65,000 years (Broome 2002; Edwards 2007). Aboriginal and Torres Strait Islander cultures are characterised by holistic and collective approaches to governing societies with complex systems of lore, kinship, spirituality, agriculture, economics and science which enabled the population not just to survive but to thrive (Broome 2002; Edwards 2007).

It is difficult to establish the exact population of Aboriginal and Torres Strait Islander people prior to European invasion, however, it is estimated that there were approximately 750,000 people, 250 distinct groups, using over 500 dialects (Broome 2002; Charlesworth 1990; Dudgeon & Walker 2015). These traditional owner groups are defined as a group of Aboriginal and Torres Strait Islander people who inhabit and belong to a definite area of Country, use a language known mainly by them, are known by a distinct name and have their own rites, customs and beliefs that are different from others (Edwards 2007), today these are often referred to as language groups or individually by their language group. There are also differences in the economic, political and social organisation of language groups (Charlesworth 1990).

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Map of Indigenous Australia (Figure 1.1) represents the general nations of Aboriginal and Torres Strait Islander groups. Whilst covering vast geographic locations, with diverse experiences, Aboriginal and Torres Strait Islander communities share many commonalities in underlying cultural values and social structures.



Figure 1.1: AIATSIS Map of Indigenous Australia

This map attempts to represent the language, social or nation groups of Aboriginal Australia. It shows only the general locations of larger groupings of people which may include clans, dialects or individual languages in a group. It used published resources from the eighteenth century-1994 and is not intended to be exact, nor the boundaries fixed. It is not suitable for native title or other land claims. David R Horton (creator), © AIATSIS, 1996. No reproduction without permission. To purchase a print version visit: https://shop.aiatsis.gov.au/

Holistic understandings of health and wellbeing are not new for Aboriginal and Torres Strait Islander communities, however, the use of social and emotional wellbeing terminology has been more recent. The conceptualisation first emerged in the 1980s at the time of global conversations about the importance of addressing health inequalities in primary health care, particularly as part of the *World Health Organisation (WHO) Alma Ata Declaration on Primary Healthcare* (1978) (Dudgeon, Milroy & Walker 2014; Garvey 2008). These conversations contributed to the emergence of Aboriginal and Torres Strait Islander community-controlled health and medical services such as Aboriginal Community Controlled Health Organisations and Aboriginal Medical Services. Critically, the first *National Aboriginal Health Strategy* (National Aboriginal

Health Strategy Working Party (NAHSWP) 1989) emerged during this period and defined health as the physical wellbeing of an individual as well as the social, emotional and cultural wellbeing of the whole community:

"Aboriginal health does not mean the physical wellbeing of an individual, but refers to the social, emotional, and cultural wellbeing of the whole community. For Aboriginal people this is seen in terms of the whole-life-view. Health care services should strive to achieve the state where every individual is able to achieve their full potential as human beings, and must bring about the total wellbeing of their communities." (National Aboriginal Health Strategy Working Party (NAHSWP) 1989)

This evolved into a common definition for Aboriginal and Torres Strait Islander health which is regularly described as social and emotional wellbeing (Dudgeon, Milroy & Walker 2014; Swan & Raphael 1995). Whilst sharing commonalities, Aboriginal and Torres Strait Islander communities are not homogenous and communities are diverse, this means that understandings of social and emotional wellbeing may vary between communities. However, there are a range of principles which articulate interconnected wellbeing and align with cultural philosophies and values, which will be described throughout the following paragraphs (Dudgeon, Milroy & Walker 2014; National Aboriginal Health Strategy Working Party (NAHSWP) 1989; Swan & Raphael 1995).

The social and emotional wellbeing model was first presented in the second edition of the Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (Dudgeon, Milroy & Walker 2014). The first iteration was based on the aforementioned definition (National Aboriginal Health Strategy Working Party (NAHSWP) 1989) and principles of the Ways Forward National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health (Swan & Raphael 1995). Members of the Australian Indigenous Psychological Association developed the model to support utility of social and emotional wellbeing concepts for mental health practitioners (Dudgeon, Milroy & Walker 2014). The model is guided by nine principles, informed by the importance of connection to land, culture, spirituality, family and community and the ability of those factors to impact on wellbeing (Dudgeon, Milroy & Walker 2014). This model has since been adapted in various contexts including the most recent National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (Australian Department of

Health and Ageing 2013) (Figure 1.2). The social and emotional wellbeing model and underpinning principles are described in detail in the following section.

Figure 1.2: Social and Emotional Wellbeing Model adapted from Gee et al 2014 in the National Aboriginal and Torres Strait Islander Health Plan 2021-2031



National Health Plan adapted from Gee, Dudgeon, Schultz, Hart and Kelly, 2014

Dreaming stories of Aboriginal and Torres Strait Islander cultures explain the origin of the natural and social world, the role of humans within this world and where they fit within wider aspects of spiritual existence (Edwards 2007). It is believed that spirit beings existed in the air, water, plants and animals, and emerged to form the earth, rocks, waterholes and other phenomena of the environment in which people live (Edwards 2007). *Connection to spirituality and culture* is described as the systems of ancestral knowledge including stories, rituals and ceremonies which connect people to place and create opportunity for Aboriginal and Torres Strait Islander people to experience a strong relationship to cultural knowledges and practices (Dudgeon, Milroy & Walker 2014).

Risks to this connection include ongoing colonial impacts and attempts of destruction which have eroded cultural values and practices and contributed to loss of languages and cultural knowledge (Butler et al. 2019). In a colonial context and as part of engagement with other cultures spirituality is considered to be an evolving expression of cultural identity (Dudgeon, Milroy & Walker 2014). Knowing about history and culture is fundamental to identity (Butler et al. 2019). Practising culture through ceremony, events, language, songs, storytelling and sharing, and caring for Country have shown to be positively associated with feeling happy (Biddle & Crawford 2017; Butler et al. 2019).

Aboriginal and Torres Strait Islander cultures have a deep connection to place with many significant sites connected to ancestor spirits (Bourke 1980). Aboriginal and Torres Strait Islander groups care for these sites and participate in ceremony to draw on the power of the ancestors, and in doing so ensure an ongoing harmony between people and Country (Bourke 1980). Connection to Country is deeply connected to spirituality, culture, identity, law, language and ceremony. The relationship to land or place is considered to provide a profound sense of wellbeing and belonging (Butler et al. 2019; Dudgeon, Milroy & Walker 2014). Access to traditional lands is integral to health for Aboriginal and Torres Strait Islander people and supports connection to family, community, Country and cultural identity. Maintaining and strengthening these cultural connections contributes to positive states of wellbeing (Kingsley et al. 2013). Connection to Country is not just the connection to physical place but a connection to what it means to be an Aboriginal and Torres Strait Islander person with a reciprocal relationship with Country where people are care takers and Country as a provider, often referred to as a mother or parent (Butler et al. 2019). Climate change, urbanisation and other modern challenges pose significant threats to Country and the ability to engage with and care for Country (Butler et al. 2019; Green & Minchin 2014). Connection to Country is maintained though land management, walking and sharing stories which all provide opportunities to escape from daily pressures and maintain this connection (Butler et al. 2019; Kingsley et al. 2018).

The Dreaming governs how people interact, behave towards each other and how society is structured and provides each person with a sense of belonging (Broome 2002). Aboriginal and Torres Strait Islander groups experience strong kindship ties, sharing the same world view and supporting each other (Broome 2002). Family and kinship provides individuals with an understanding of their status, roles, what is expected of them, what

they can expect of others, who they are related to, and what their relationships mean (Dousset 2018). Aboriginal and Torres Strait Islander social and kinship systems are based on sharing and support to govern relationships with each other and to the land (Ellis 2007). Connection to Family and community provide structure and understandings of obligations within and between people and communities and are fundamental to identity and a sense of self. The collective nature of Aboriginal and Torres Strait Islander relationships means that connection to community is fundamental in supporting a sense of belonging and contributing to social capital and resources. These relationships are also understood to include relationships beyond immediate blood relatives and include broader connections of kinship and social structures (Butler et al. 2019; Dudgeon, Milroy & Walker 2014). People are connected, not necessarily by place alone, but by shared cultural knowledge and values which contributes to their sense of identity; by participation in family and community life people are interconnected and through reciprocal relationships take care of each other (Butler et al. 2019). The ability to maintain connections and shared, reciprocal family and community networks and values is challenged by the ongoing impacts of colonisation and policies of assimilation, and dominant Western individualistic values (Browne-Yung et al. 2013; Butler et al. 2019). Opportunities for social and cultural connection, including through sporting clubs and events, are considered to support mental health and wellbeing (Browne-Yung et al. 2013; Butler et al. 2019).

Connection to body, mind and emotions include aspects of health and wellbeing which relate to the body, individual or intrapersonal experience (Dudgeon, Milroy & Walker 2014). The available evidence on pre-colonial health practices relies on early colonial documents, archaeological remains and anthropological studies (Carson et al. 2007). These understandings indicate that while Aboriginal and Torres Strait Islander communities experienced illnesses prior to colonisation, these are believed to be mild compared to those experienced through the arrival of a number of introduced diseases (Carson et al. 2007). Connection to body includes physical wellbeing such as the biological aspects of physical health, for example, poor self-assessed health status has been linked with lower levels of happiness for Aboriginal and Torres Strait Islander people (Biddle 2014b). Western biomedical definitions of physical health do not align well with Aboriginal and Torres Strait Islander definitions of connection to body, which view physical health as interconnected with the mind and spirit (Biddle 2014b; Butler et

al. 2019; Dudgeon, Milroy & Walker 2014). Strong physical health and wellbeing is described as the ability to participate fully in life and supports connections and responsibilities to other domains of wellbeing such as family, community and Country (Butler et al. 2019; Dudgeon, Milroy & Walker 2014).

Connection to mind and emotions refers not just to the presence or absence of mental health but also cognitive, emotional, psychological factors which can define the human experience, including safety and security, sense of belonging, control and mastery, secure relationships and so forth (Dudgeon, Milroy & Walker 2014). In understanding connection to mind and emotions within the evidence, there are challenges caused by the conflated way in which social and emotional wellbeing is often described as a domain of wellbeing (alternate term for mental health) rather than another term for wellbeing (Butler et al. 2019). This has resulted in fairly limited cultural understandings of the link between mental health on or with social and emotional wellbeing more broadly (Butler et al. 2019). This terminology while commonly used, has been part of ongoing confusion given its origins in mental health and frequent use to describe mental health or mental illness. The absence of culturally defined language or understandings of mental health has contributed to use of the term social and emotional wellbeing as reflecting mental health (Garvey 2008). In interpreting social and emotional wellbeing frameworks, mental health appears as a domain of social and emotional wellbeing, and not the same as social and emotional wellbeing. Despite these challenges, mental health is considered to significantly impact on social and emotional wellbeing with psychological distress and mental health outcomes extensively documented, including the role of ongoing colonial racism, marginalisation and dispossession (Butler et al. 2019; Calma, Dudgeon & Bray 2017).

The social and emotional wellbeing model as articulated by Gee et al. (2014) recognises the role of macro factors on health and wellbeing, including the cultural, historical, political and social determinants (Dudgeon, Milroy & Walker 2014). These macro factors have become well known in health research literature as the *Determinants of Health* (Solar & Irwin 2010). The social and emotional wellbeing model presented earlier in this Chapter (Figure 1.2) effectively articulates the nuances and differences between these determinants consistently with Aboriginal and Torres Strait Islander ways of knowing, being and doing (Dudgeon, Milroy & Walker 2014; Martin-Mirraboopa 2003). Each of these factors are introduced in the following paragraphs.

Cultural determinants centre Indigenous definitions of health and focus on holistic health concepts, family, community, Country and culture, which can provide strength, resilience and empowerment to communities (Solar & Irwin 2010; Verbunt et al. 2021). There are a range of cultural determinants of health that still need to be collectively defined and understood and the conceptualisation of the social and cultural determinants of health for Aboriginal and Torres Strait Islander communities within the literature is emerging (Verbunt et al. 2021).

Historical determinants recognise the historical oppression of Aboriginal and Torres Strait Islander communities as part of colonisation, destructive past government policies and their ongoing impact on the experiences of individuals and communities (Dudgeon, Milroy & Walker 2014).

Aboriginal and Torres Strait Islander *political determinants* include the unresolved individual and collective rights of Aboriginal and Torres Strait Islander people including land rights, self-determination, control and sovereignty (Dudgeon, Milroy & Walker 2014; Marmot et al. 2008; Solar & Irwin 2010). Political determinants include decisions made by politicians or in politics which impact on health and wellbeing (Mackenbach 2014; Solar & Irwin 2010). These decisions might include laws, taxes, public policies, and services (Mackenbach 2014; Solar & Irwin 2010).

Political determinants or outputs from political decisions along with the historical, environmental and cultural context in which they exist continue to be shaped by the *structural determinants*. Structural determinants refer to the societal systems, structures, values, norms and everyday practices of society (Solar & Irwin 2010; WHO Commission on Social Determinants of Health 2008)). This includes forms of oppression which can be systematically reproduced in economic, political and cultural institutions, for example racial discrimination (Solar & Irwin 2010; WHO Commission on Social Determinants of Health 2008).

Social determinants are the social conditions in which people live and include employment, housing, education, and access to resources, all of which impact on health and wellbeing (Marmot et al. 2008; Solar & Irwin 2010; Zubrick et al. 2014). The context in which people live, determines their health and includes factors which influence health and wellbeing, or put simply influence the likelihood of someone becoming sick or being healthy (Solar & Irwin 2010; WHO Commission on Social Determinants of Health 2008).

The ongoing oppression and dispossession of Aboriginal and Torres Strait Islander communities has contributed to significant social and health inequities and there is undoubtedly a link between invasion and centuries of poor health and wellbeing which have followed (Gracey & King 2009).

# 1.2 Historical determinants: Surviving the attempted systematic destruction of Aboriginal and Torres Strait Islander people and culture

"Only by Australians knowing the past - the good and the bad, by understanding how we got where we are, will it be possible for all of us to move on. There is no moving on without first looking back." Hall (1998) p.2

In 1788 the First Fleet arrived in Australia, and with the founding myth of terra nullius, thriving people were reduced to the same status as animals, flora and fauna (Banner 2005). This was followed by a purposeful period of the active attempted destruction of a culture and people, which would shape the trajectory and outcomes of the population for decades to come (Hall 1998). Charles Darwins' racialised theories of humanity, 'survival of the fittest' and other theories of the time generated by Western science shaped first encounters and the subsequent policies and practices which were implemented in colonial Australia (Barta 2005). During early contact, the years that followed and even currently, racial theories have shaped the relationship between Aboriginal and Torres Strait Islander people and non-Indigenous Australians (Chambers 1986). The concept of 'race' emerged from ideas that there are specific groupings of people who share common physical and/or biological characteristics (McConnochie 1988). Racial theories underpinned the use of these different characteristics to explain inferiority and superiority of people (Zelinka 1996). In an Australian setting, use of racial theories and dominant-culture perceptions have continued to shape the policies, actions and narratives which impact on Aboriginal and Torres Strait Islander peoples (Barta 2008; Broome 2002; Dudgeon, Bray & Walker 2023; Kairuz et al. 2021).

The period post 1788 for Aboriginal and Torres Strait Islander communities was one of extreme violence. The narratives located in history books were constructed by Europeans, based on the European perspective and largely excluded the lived experiences of Aboriginal and Torres Strait Islander peoples (Macintyre 2003; Stastny 2019). In 1968, anthropologist William Stanner delivered a history changing lecture to highlight what he called the 'Great Australian Silence' (Foster 2003). He suggested that the accounts and records of history failed to integrate the story of dispossession and its effects (Manne 2003). Historians continue to attempt to re-write history and ensure truth telling about the murder, rape, fear and hatred that were part of forming the colony of Australia (Reynolds 1999). This period was characterised as the Frontier Wars which took place between 1788-1940s. There are many graphic accounts of frontier violence available in the records

that highlight how racism and the perception of European superiority enabled dispossession and subjugation of Aboriginal and Torres Strait Islander peoples (Barta 2005; Chambers 1986). Racism is still experienced daily and some frontier conflicts are still vividly remembered by Aboriginal and Torres Strait Islander people across Australia (Paradies 2016; Reynolds 1999). While racial theories have been discredited, their legacy continues in every day literature, media and conversations in Australian society (Edwards 2007; Hall 1998). The impact of these theories is evident in policies and practices, namely the assimilation policies which were in place well into the 1960s, where state law sanctioned the forcible removal of Aboriginal and Torres Strait Islander children from their families (Healey 2019; National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997). Assimilation policies aimed to separate 'full bloods' from the 'half castes' and inhibit the reproduction of Aboriginal and Torres Strait Islander people (Healey 2019; McConnochie 1988; National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997). Australia's assimilation policies were forms of genocide intent on the destruction of Aboriginal and Torres Strait Islander people and cultures (Barta 2005, 2008; National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997; Paradies 2016; Robinson & Paten 2008). Aboriginality was viewed as a problem and the removal of mixed descent children was justified to prevent 'undesirable cultural practices and traditions' (Barta 2008; National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997).

In 1995 there was National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families followed by the release of the Bringing Them Home report in 1997 (National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997). The inquiry found that children were taken at any age, sometimes within days of their birth and were most often institutionalised (National Inquiry into the Separation of & Torres Strait Islander Children from their 1997). Aboriginality was not positively affirmed, children's culture and parents were often demeaned and many children told that their families did not want them or were deceased (National Inquiry into the Separation of & Torres Strait Islander Children from their 1997). The removal of a primary carer without replacement by someone to whom the child can form a loving and strong attachment has serious consequences. Research on the implications of separating infants from their primary carer and placing them in

institutions has been linked to the development of psychiatric disorders in later life, such as anxiety and depression (National Inquiry into the Separation of & Torres Strait Islander Children from their 1997). Other impacts of the forcible removal of children from their families included loss of connection to culture, loss of identity and self-esteem, higher likelihood of mental health problems as well as health, housing and education challenges (National Inquiry into the Separation of Aboriginal Torres Strait Islander Children from their Families 1997). The effects have been significant, far reaching, and intergenerational and still impact many families today (National Inquiry into the Separation of & Torres Strait Islander Children from their 1997).

Through the systematic dismantling of Aboriginal and Torres Strait Islander culture, people were actively and violently removed from their Country, children were forcibly removed from their families, and languages were silenced (Reynolds 1999). The effects of this were a fracturing of culture, connection, identity and the attempted erasure of Aboriginal and Torres Strait Islander ways of knowing, being and doing (Paradies 2016). The introduction of diseases, changes to lifestyles, food and resources, access to Country and knowledge for cultural practices, restrictions on movement, exclusion from society and access to basic rights have all shaped the post-colonial health and wellbeing of Aboriginal and Torres Strait Islander populations (Paradies 2016). A history of racism, violence and the dispossession of land and their associated government policies and responses have significantly shaped contemporary lived experiences (Barta 2005; Chambers 1986; Hall 1998; Markwick et al. 2019; Paradies 2016). These intergenerational impacts have continued to shape Aboriginal and Torres Strait Islander peoples' health and wellbeing today.

### 1.3 Political determinants: Sovereignty never ceded

"To enact an existence that is always love and resistance demands of us a deliberate conscious decision to find joy – not away from the fight, but in the fucking fight."

Chelsea Watego (Watego & Watson 2021) p.227

Aboriginal and Torres Strait Islander communities have been fighting for rights, recognition and sovereignty in some form or another, from the moment the First Fleet arrived (Archibald et al. 2019; McGregor 2009). Politics deeply influences all structures of society, and directly so, in policies, programs and service delivery (Zubrick et al. 2014). Governments have a duty to promote the inclusion and wellbeing of all citizens enabling participation in social, economic and civic life (Zubrick et al. 2014). There has been both progress and ongoing political failures in Aboriginal and Torres Strait Islander affairs. Throughout the 1960's activism was used to advocate to politicians and policy makers. An example of this success was with the late Charles Perkins leading a group of non-Indigenous University of Sydney students on the 'Freedom Rides' to raise awareness and draw attention to the discrimination, segregation and poor treatment being experienced by Aboriginal and Torres Strait Islander people (Chesterman 2001; McGregor 2009). This is one of many examples of activism in the 1960s which drew international attention towards Australia's treatment of Aboriginal and Torres Strait Islander people and was the foundation for the 1967 Referendum (Chesterman 2001).

The 1967 Referendum was an important step in enabling Aboriginal and Torres Strait Islander people to have political representation and a 'voice' nationally (Lake 2002). The referendum ensured the removal of two racially discriminatory parts of the Australian Constitution (Chesterman 2001). Section 127 was removed as part of the referendum and enabled the Commonwealth, in conjunction with the States, to legislate for Aboriginal and Torres Strait Islander people, including being counted in the Australian population Census<sup>1</sup> for the first time (Chesterman 2001). Fifty years later, a constitutional convention brought together over 250 Aboriginal and Torres Strait Islander leaders from across the nation to discuss constitutional reform (Mckay 2017; Referendum Council 2017).

<sup>&</sup>lt;sup>1</sup> The Australian Bureau of Statistics implements the Census of Population and Housing (the Census), which collects a range of demographic and socioeconomic information of the entire population.

In 2017 at the foot of Uluru<sup>2</sup>, also known as the nations 'heart', the 'Uluru Statement from the Heart' was produced (Mckay 2017; Referendum Council 2017):

"We seek constitutional reforms to empower our people and take a rightful place in our own Country. When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their Country."

Uluru Statement from the Heart (Referendum Council 2017)

The Uluru Statement from the Heart articulates the need for the establishment of a 'First Nations Voice' in the Australian Constitution and a 'Makarrata Commission' which is more aligned to a treaty process, recognising that sovereignty of these Lands and Waters was never ceded by Aboriginal and Torres Strait Islander people (Mckay 2017; Referendum Council 2017).

One of the most consistent and continuing initiatives 'for' Aboriginal and Torres Strait Islander people has been the Australian Governments' commitment to *Closing the Gap* which has bound all facets of government (Federal, State and Local) to improve the lives of Aboriginal and Torres Strait Islander communities (Rudd 2009). In 2005, the Aboriginal and Torres Strait Islander Social Justice Commissioner's report urged the Australian Government to commit to closing the health life expectancy gap for Aboriginal and Torres Strait Islander people. By 2009, the Council of Australian Governments (COAG) reform agreement laid out six Closing the Gap Targets for life expectancy, infant mortality, literacy and numeracy, education and employment. The Closing the Gap Report is produced annually as a report to Parliament on progress towards the targets (Productivity Commission 2021). Over the years there have been improvements in various indicators and measures, however, the recent Closing the Gap refresh highlighted the need for a new way of working with communities, the end of government defined targets and a focus on self-determined approaches (Productivity Commission 2021).

Aboriginal and Torres Strait Islander activism has continued well into the 2000s with many of the same requests from the 1960s which continue to go unmet including not being afforded sovereign rights which impedes self-determination (McGregor 2009). Notable achievements of continued activism have included the *Mabo* High Court decision in 1992 which recognised Aboriginal and Torres Strait Islander land rights, over-turned

<sup>&</sup>lt;sup>2</sup> Uluru is a large sandstone formation in the centre of Australia which has cultural significance for Mutitjulu people.

the myth of terra nullius, and allowed for the subsequent *Native Title Act*, which enabled claims to be made over traditional land ownership (Foley & Anderson 2006). Critiques highlight that while this was a landmark decision it is mostly an illusion of land ownership and is not governed by communities as it should be (Foley & Anderson 2006).

There are inter-related and multi-layered relationships between the justice system and social and emotional wellbeing, with offenders more likely to have mental health and substance use illnesses which are heavily influenced by the historical, political and social determinants of health, particularly, being a member of the 'Stolen Generations' (Zubrick et al. 2014). In 1987, there was a *Royal Commission into Aboriginal and Torres Strait Islander Deaths in Custody* with people dying in custody at unacceptable rates. A range of recommendations were made at the time and many remain unimplemented (Cubillo 2021). The 2008 National Apology to the Stolen Generations, delivered 11 years after the 1997 *Bringing them Home Report*, fell short of any real or meaningful change (Barta 2008). The same for a plethora of other reports and Royal Commission inquiries and recommendations on the "Indigenous problem" while Aboriginal and Torres Strait Islander people continue to experience adverse outcomes on all indicators of health and wellbeing (Bond et al. 2020). In 2020, during the height of the international Black Lives Matter<sup>3</sup> movement, Aboriginal and Torres Strait Islander people took to the streets during a global pandemic to demand justice (Bond et al. 2020; Dudgeon & Walker 2022).

Aboriginal and Torres Strait Islander social and emotional wellbeing promotes self-determination, and the effective functioning of communities plays a critical role in supporting holistic wellbeing (Zubrick et al. 2014). Embedding cultural practices in daily life fosters personal and cultural identity which is a necessary protective factor of health and wellbeing (Biddle 2014b; Biddle & Crawford 2017; Zubrick et al. 2014). Self-determination creates space for the 'strength, capability and humanity of Aboriginal and Torres Strait Islander peoples, services and communities in all processes of health policy formation and implementation, not as partners but as architects' (Bond et al. 2020). In a current context, social and emotional wellbeing lived experiences are undoubtedly shaped by the history of political decisions which have contributed to dispossession, exclusion, discrimination, marginalisation and inequality (Browne-Yung et al. 2013; Dudgeon,

<sup>&</sup>lt;sup>3</sup> Black Lives Matter is an international social movement emerging from the United States which highlights racism, discrimination, and racial inequality experienced by black people, particularly police brutality and racially motivated violence.

Milroy & Walker 2014; Zubrick et al. 2014). Self-determination is necessary to enable embedded culturally responsive approaches across politics, policy and service delivery that promotes social and emotional wellbeing (Dudgeon et al. 2017).

### 1.4 The social determinants of health and the pursuit of equity in the 'colony': a compelling call to action

"There remains a pressing need to question inequality in Australian society, and to question how we protect the most vulnerable among us." Calma (2008)

It has been established in this chapter that the social determinants of health continue to shape health and wellbeing. To support cultural and contextual understandings of these social determinants of health the following section briefly describes each of these determinants and how they relate to Aboriginal and Torres Strait Islander health and wellbeing.

Education supports health and economic outcomes through increased health literacy, access to services and employment opportunities (Carson et al. 2007). Education attainment is linked with increased opportunities in life, better employment or earning capacity to access life essentials and health literacy to make decisions about health and wellbeing (Biddle 2006; Johnston, Lea & Carapetis 2009).

Employment, or unemployment for Aboriginal and Torres Strait Islander people is influenced by pervasive racism, social exclusion and oppression (Walter 2016). Exclusion from education settings and Western education systems have left Aboriginal and Torres Strait Islander populations with unequal access to employment (Burridge & Chodkiewicz 2012). Employment often accompanies education and income as a socio-economic factor that is considered to influence health and wellbeing. Financial security and financial resources enhance wellbeing by increasing social capital, reducing chronic stress and supporting access to basic needs such as medication and nutritious food which support health and wellbeing (Carson et al. 2007).

Income has been established as being a sound measure of material resources which can contribute to improved health and wellbeing (Darin-Mattsson, Fors & Kåreholt 2017). Income has been shown to directly shape living conditions including access to resources including food and health care as well as health behaviours such as quality of diet and physical activity and the ability to afford safe and adequate housing and healthcare (Markwick et al. 2014).

Housing conditions have been well evidenced as fundamental to health, with crowded housing contributing to a range of health conditions (Australian Institute of Health and

Welfare 2022; Bailie & Wayte 2006). Access to appropriate, affordable and secure housing is considered an important factor in health and wellbeing (Australian Institute of Health and Welfare 2021b). Housing is interconnected with other social determinants of health with low-income earners, unemployed or underemployed at greater risk of poor quality housing (Baker et al. 2016). The social determinants of health are associated with greater mental health risks, and individuals with a lower socio-economic status have a higher prevalence of mental illness compared to individuals with a higher socio-economic status (Allen et al. 2014).

Aboriginal and Torres Strait Islander communities have long been characterised by deficit discourses and narratives (Walter 2018). Whilst priority should always be given to highlighting stories of strength and resilience (Bryant et al. 2021), it is necessary to contextualise unacceptable health outcomes while emphasising ongoing failures of health and social system responses (Bond et al. 2020). Quantitative data and statistics are widely used to systematically provide information about the health of the population, in Australia this is often in the form of official statistics and administrative data collected as part of the provision of health care services (Biddle 2014a). Aboriginal and Torres Strait Islander health and social needs have been extensively documented in health reports produced by different sources for different purposes including to develop population level understandings and monitor progress towards plans and priorities (Australian Bureau of Statistics 2020; Australian Institute of Health and Welfare 2020a, 2021a; Productivity Commission 2021; Walter et al. 2021).

National key reports show that outcomes are extensively monitored across similar complex, and inter-related factors, for example, chronic conditions, mental health, employment and education. (Australian Institute of Health and Welfare 2020a, 2021a; Productivity Commission 2021; Steering Committee for the Review of Government Service Provision 2020). Detailed comparisons between Aboriginal and Torres Strait Islander and non-Indigenous populations have been documented and analysed by urban, rural and remote regions with variations in health and social outcomes widely observed (Anderson et al. 2006). These reports do not tell a hopeful story, particularly for mental health needs which have significantly worsened over time (Australian Institute of Health and Welfare 2020a). Between 2006 and 2019, there was a 61% increase in the imprisonment rate for Aboriginal and Torres Strait Islander adults (from 1,337 to 2,088 per 100,000 persons) (Australian Institute of Health and Welfare 2020a). In 2014–18,

there was a 49% increase in suicide rates, the rate of hospitalisation due to intentional self-harm increased by 120% for Aboriginal and Torres Strait Islander females and 81% for Aboriginal and Torres Strait Islander males (Australian Institute of Health and Welfare 2020a). In 2018-19, one third (31%) of Aboriginal and Torres Strait Islander adults reported high or very high levels of psychological distress (Australian Institute of Health and Welfare 2020a). These longstanding significant outcomes highlight the need to better understand and respond to health and social needs.

The health care system in Australia is heavily focused on biomedical understandings of health and the physical or biological aspects of disease without recognition of the impact of external factors, for example, education, employment, housing and income, on health and wellbeing (Carson et al. 2007). Current health care approaches remain inadequate, focusing on symptoms instead of root causes, which continues to inhibit progress towards improving health outcomes (Holland 2018). These Western models of health do not recognise or respond to Aboriginal and Torres Strait Islander knowledges and world views (Dudgeon, Bray & Walker 2023; Laverty, McDermott & Calma 2017). In addition, there are many potential complex and interconnected contributing factors to health and social outcomes including racism, marginalisation and continued systematic oppression having significant consequences (Bond et al. 2020; Paradies 2016).

Evidence continues to highlight the gap between what is known about the impact of the social determinants of health at a population level and actions to address these determinants (Bambra et al. 2010; Fisher et al. 2016; Tallon et al. 2017). There is currently no systematic approach in and across the health system to address the social determinants of health that respond in practice to the breadth of social and cultural needs for Aboriginal and Torres Strait Islander communities (Gupta et al. 2020; Osborne, Baum & Brown 2013). Additionally, there remains pressing need for evidence-based programs with high quality evaluation (Kelaher et al. 2018). Programs which have focussed on addressing social and cultural needs for Aboriginal and Torres Strait Islander people have produced evidence of increased access to necessary care and improved clinical outcomes in participants (Askew et al. 2016). Future research focus is required to generate practice-based understandings of how to take action in practice to address the social determinants of health to promote social and emotional wellbeing. Such approaches necessitate the generation of foundational understandings which align with Indigenous knowledges, utilising an Indigenous methodology.

Indigenous knowledge underlies this mixed-methods PhD program of work which aims to build foundational understandings on approaches to address social determinants of health and promote action in practice on social and emotional wellbeing.

An Indigenous methodology underpinned the PhD program of work's iterative research design which included prioritising Indigenous ways of knowing, being and doing, insider approaches and Indigenous governance and leadership. An Indigenous methodology supports generating understandings which are strengths-based, culturally aligned and avoids deficit narratives. The thesis will further understandings by exploring unmet needs and how these are experienced in different places in different ways within South Australian Aboriginal and Torres Strait Islander communities. To inform action in practice, the research program will seek to understand current health care approaches to addressing the social determinants of health. These understandings informed the development, implementation and evaluation of a program producing practice evidence as a foundation for knowledge to action on the social determinants of health to promote social and emotional wellbeing. The research objectives are to:

- 1. Explore the geographic variations in community level outcomes for mental health and the social determinants of health for South Australian Aboriginal communities.
- Conduct a scoping review to identify health programs that address the social determinants of health and outline the extent that program delivery aligned with Aboriginal and Torres Strait Islander knowledges.
- 3. Undertake a developmental evaluation of an initiative addressing unmet social and cultural needs of Aboriginal and Torres Strait Islander South Australians.

#### 1.5 Thesis overview

This thesis is structured as a story telling process to share key foundational understandings which shape action in practice on the social determinants of health to promote social and emotional wellbeing. This thesis follows the model of conventional chapters combined with peer reviewed publications. A schematic representation of the structure and organisation of this thesis is displayed in Figure 1.3.

Chapter 1 Chapter 3 Study 1: Explore Introduction Describes communitylevel mental health Chapter 6 Conceptualises Chapter 5 outcomes and social holistic health and determinants of wellbeing. health in South Australia. Discussion and Conclusion Chapter 2 Chapter 4 Evaluation of a program which aimed References and to address unmet Appendices existing programs social and cultural needs of Aboriginal Scoping review and Torres Strait Islander South Outlines bringing together Australians Indigenous evidence of existing health care program Methodology and addressing the social study context. determinants of health.

Figure 1.3: Schematic representation of structure and organisation of thesis

#### Outline of the thesis

Chapter Two outlines the underpinning Indigenous methodology and research design framework which integrates knowledges, draws on strengths of the researcher and engages in participatory approaches with the community. The chapter contextualises Aboriginal and Torres Strait Islander demographics nationally and in South Australia as well as positioning this program of work within an Aboriginal and Torres Strait Islander research theme which is informed by community priorities. Data used throughout this chapter and subsequent chapters are contemporaneous to the iterative design and reflective of when each study was implemented.

Chapter Three (Study 1) describes *community-level mental health outcomes and social determinants of health in South Australia*. This chapter as the first study highlights key considerations for data collection measures in relation to social factors and mental health

and provides community level insight into outcomes within and between communities. Community level understandings can support tailored and relevant action.

Chapter Four (Study 2) is a scoping review bringing together *evidence of existing health care programs* addressing the social determinants of health in culturally relevant ways. Chapter Four is structured in two parts, the first describes a scoping review methodological enhancement and the second part articulates the results of a scoping review aimed at *identifying health care programs for Aboriginal and Torres Strait Islander people which address the social determinants of health*. This review contributes to culturally relevant understandings of existing evidence addressing the social determinants of health which can inform action in practice on the social determinants of health.

Chapter Five (Study 3) evaluates the implementation of a social determinants of health intervention, known as the Cultural Pathways Program. This chapter was informed by Study 2 and Study 3 and details the developmental evaluation findings for the Cultural Pathways Program which through reflective and formative methods supports further understanding on the interactions between Facilitators, program participants and the broader health and social service contexts through service connections. The chapter is structured in two parts with the first describing the Cultural Pathways Program approach and the second part describing the implementation and evaluation.

Chapter Six combines understandings from across all three studies to articulate a framework to take action in practice on the social determinants of health. This chapter highlights the methodological, theoretical, systems and practice implications of this program of work and recommendations to build upon in future research. Consistent with the Indigenous methodology this chapter details the translation activities which are contributing to changes in the policies, systems and practices which contribute to health and wellbeing outcomes for Aboriginal and Torres Strait Islander communities.

## CHAPTER TWO: METHODOLOGY AND CONTEXT

#### 2.1 Introduction

"We are proud advocates and activists for our people. We march and we protest. We publish and we critique. We confront wilful blindness and we will not be silenced. We research to empower our community and build our communities. We research to honour the history and battles of our ancestors and we research to arm the next generation of warriors." Larissa Behrendt in Archibald et al. (2019) p.185

All social spaces or places are invested with social meaning which is drawn from lived experience (Neubauer, Witkop & Varpio 2019). Building upon understandings of cultural knowledge, history and unmet needs presented in Chapter One, this chapter outlines and situates the context of this research. Aboriginal and Torres Strait Islander population demographics, understandings of the health and social needs and priorities of communities and the most appropriate methods and approaches to address the identified needs in a research setting are outlined.

The relationship between Aboriginal and Torres Strait Islander communities and non-Indigenous researchers has been tenuous. Knowledge created about Indigenous people by non-Indigenous people has been utilised to implement policies and practices that have caused harm (Archibald et al. 2019; Moreton-Robinson 2013; Smith 2012). Moreton-Robinson highlights that for Indigenous populations, knowledge has been used for power and control (Moreton-Robinson 2000). Whilst research with Aboriginal and Torres Strait Islander communities and by Aboriginal and Torres Strait Islander researchers has evolved over time, research has undoubtedly perpetuated oppression and disempowered communities, presenting 'them as problems' and positioning communities as 'subjects' of research (Archibald et al. 2019; Cochran et al. 2008; Laycock 2011; Simonds & Christopher 2013). For decades, research with Indigenous populations was characterised by dominant discourses that positioned non-Indigenous science as having the solutions to 'Indigenous problems' failing to recognise the very existence of those problems were a result of decades of racism, discrimination, dispossession and oppression (Moreton-Robinson 2004, 2013; Smith 2012; Walter & Andersen 2013; Wilson 2008).

The emergence of Indigenous and decolonising methodologies by Indigenous scholars has created opportunities for researchers to prioritise Indigenous knowledges as an active reclamation of space, an act of colonial resistance and self-determination (Archibald et

al. 2019; Brown & Strega 2005; Smith 2012). An Indigenous methodology is underpinned by ways of being (ontology / how we perceive our reality), ways of knowing (epistemology / how we think about it), and ways of doing (axiology / values and beliefs) (Dudgeon et al. 2020; Martin-Mirraboopa 2003; Moreton-Robinson 2004; Rigney 1999; Rowe, Baldry & Earles 2015; Smith 2012; Wilson 2008). Indigenous methodologies are culturally relevant and responsive to the needs of Indigenous communities (Archibald et al. 2019; Chilisa 2012; Dudgeon et al. 2020; Martin-Mirraboopa 2003; Moreton-Robinson 2013; Nakata 2002; Rigney 1999; Smith 2012; Wilson 2008).

This chapter outlines the research design framework which utilises an Indigenous methodology to integrate Indigenous and non-Indigenous knowledges at the interface (Durie 2004). The methodology of this PhD applies an Indigenous standpoint to position the researcher as an insider (Moreton-Robinson 2013; Nakata 2002). As an insider the researchers strengths are utilised to implement participatory approaches with the community that consider various historical, social, political and cultural contexts which shape the lived experiences of Aboriginal and Torres Strait Islander communities (Bainbridge et al. 2011; Berger 2013; Blix 2015; Dickson 2020; Dwyer & Buckle 2009; Kendall et al. 2011; Martin-Mirraboopa 2003; Moreton-Robinson 2013; Ortlipp 2008).

#### 2.2 Indigenous Methodology

'Knowledge is never innocent or neutral, it is a key to power and meaning and is used to dominate and control' Moreton-Robinson (2000, p. 93)

An Indigenous methodology can include both Indigenous and non-Indigenous methods but is always consistent with Indigenous ways of knowing, being and doing (Martin-Mirraboopa 2003; Moreton-Robinson 2004; Rigney 1999; Smith 2012; Wilson 2008). It generally starts with Indigenous knowledge and understanding and then identifies the most appropriate method to meet that need (Martin-Mirraboopa 2003; Moreton-Robinson 2004; Rigney 1999; Smith 2012; Wilson 2008). If required, those methods are then adapted to incorporate or better suit Indigenous ways of knowing, being and doing (Martin-Mirraboopa 2003; Moreton-Robinson 2004; Rigney 1999; Smith 2012; Wilson 2008). An Indigenous methodology can utilise either quantitative or qualitative methods (or both) depending on the question of interest (Simonds & Christopher 2013; Walter & Andersen 2013; Wilson 2008).

Indigenous quantitative methodologies provide an alternative epistemological, ontological and axiological approach to the creation, analysis and interpretation of Indigenous data (Simonds & Christopher 2013; Walter & Andersen 2013). Quantitative research methods aim to measure and analyse relationships between variables in a value free or 'objective' way (Sale, Lohfeld & Brazil 2002). Indigenous quantitative methodologies centre Indigenous ways of knowing, being and doing to disrupt harmful and deficit-based approaches which reduce Indigenous people to subjects or numbers, viewed and understood from non-Indigenous perspectives (Simonds & Christopher 2013; Walter & Andersen 2013).

Indigenous voices and epistemologies must be central to the research process and researchers need to critique underlying assumptions and methods of non-Indigenous paradigms, before adapting or applying them to Indigenous communities and contexts (Rowe, Baldry & Earles 2015; Simonds & Christopher 2013; Smith 2012). Qualitative research methods explore peoples lived experience and perspectives to enhance understanding of lived human experiences, often complex and contextual, influenced by historical, social and political factors (Denzin 1989; Neubauer, Witkop & Varpio 2019). Indigenous qualitative methods enable relational and relationship-based approaches, yarning, story-telling and sharing (Bennett et al. 2013; Bessarab & Ng'Andu 2010; Wilson

2008). A mixed-methods approach combines quantitative and qualitative methods for complementary purposes to support holistic and culturally relevant understandings which are difficult to obtain solely from one approach or method (Chilisa & Tsheko 2014; Sale, Lohfeld & Brazil 2002).

Indigenous methodologies have continued to grow in use and understanding since the 1990s. Wilson (2008) presents an Indigenous methodology timeline where prior to this period of growth there were few Indigenous academics and most were striving for inclusion and recognition. These academics were avoiding marginalisation and were generally situated within a Western framework (Wilson 2008). The significant growth in Indigenous research and scholarship throughout the 1990s challenged dominant non-Indigenous research approaches and in doing so decolonising, integrating and Indigenist research emerged in various research contexts (Rigney 1999; Smith 2012; Wilson 2008). As a result of this rapid growth and the diversity of Indigenous populations, there is no single definition of an Indigenous methodology or descriptive approach to research. The Indigenous methodology applied in this thesis is informed by a range of key methodological thinkers and approaches including:

Māori scholar Linda Tuhiwai-Smith in *Decolonizing methodologies* outlines an approach to explore dominant methodologies, theoretical and knowledge systems (Smith 2012). Through decolonization these systems are deconstructed and built anew in a way that aligns with Indigenous knowledges. Decolonizing methodologies are informed by principles of self-determination, healing, transformation and mobilisation.

Indigenist Research by Kaurna-Narungga-Ngarrindjeri scholar Lester-Irabinna Rigney (1999) outlines an approach for research by Indigenous peoples for Indigenous peoples and in the interests of Indigenous peoples (Rigney 1999). Indigenist research aims to decolonise Western research and reframe, reclaim and rename Indigenous research, to contribute to self-determination, liberation and sovereignty where Indigenous research is defined and controlled by Indigenous communities underpinned by critical analysis of dominant epistemologies (Rigney 1999). There are three core inter-related principles: Resistance (as the emancipatory imperative), political integrity, and privileging Aboriginal and Torres Strait Islander voices (Rigney 1999).

Torres Strait Islander scholar Martin Nakata (Nakata 2002) articulated Indigenous methodologies as a *cultural interface*, a theoretical framework for how Aboriginal and

Torres Strait Islander people exist within the dominant Western system and the contested space between Indigenous and non-Indigenous knowledges (Nakata 2002). Ryder et al. (2020) describe this cultural interface as similar to the process of weaving a basket and that the interconnection of both knowledge systems weaves an Indigenous methodology (Ryder et al. 2020).

Indigenous scholar Karen Martin-Mirraboopa (2003), a Noonuccal woman from Minjerripah and Bidjara ancestry posits that research is fundamentally a Western practice and, as such, a research framework that is entirely Aboriginal is not possible. It is from this perspective that Martin articulates an Indigenist research framework which defines Indigenous *Ways of knowing, being and doing as a theoretical framework and methods for Indigenous and Indigenist re-search*. Martin-Mirraboopa emphasises the social, historical and political contexts which shape experiences, lives, positions and futures. Principles of this approach privilege the voices and experiences of Aboriginal and Torres Strait Islander people in alignment with aspects of Western research frameworks to identify and redress issues of importance (Martin-Mirraboopa 2003). Further, Martin articulates importance of: Aboriginal lands, laws, elders, culture, Community and relatedness, families and futures (Martin-Mirraboopa 2003).

Opaskwayak Cree scholar Shawn Wilson (2008) in *Research is Ceremony* unravels dominant knowledge systems and provides a framework for Indigenous scholars to implement a methodology which is grounded in Indigenous ways of knowing, being and doing. Through story-telling an Indigenous methodology is outlined which shifts from appealing to dominant knowledge systems to honouring Indigenous knowledges in their own right as part of reclaiming self-determination and sovereignty of Indigenous communities (Wilson 2008). Wilson articulates principles of: relational accountability, respect, reciprocity and responsibility (Wilson 2008).

Aileen Moreton-Robinson, a Geonpul woman from Quandamooka and Indigenous feminist, developed the Indigenous Women's Standpoint Theory (Moreton-Robinson 2013). A standpoint approach responds to the notion that all knowledge is subjective and that our world views and lived experiences shape the way we understand, interpret and create knowledge (Moreton-Robinson 2013). Researchers in the creation of knowledge are not detached from their self, social, cultural and political positions and when choices are made about the research and methods, these are informed by the standpoint of the

researcher (Moreton-Robinson 2013). An Indigenous women's standpoint theory does not separate the self from Country or ancestors but instead enables an opportunity to exercise sovereignty as part of the methodology (Moreton-Robinson 2013). Principles include community responsibilities and accountability, sovereignty, relationality and relatedness (Moreton-Robinson 2013).

Whilst it is evident that these approaches and understandings emerged in nuanced ways, there is consistency across many of the underlying principles. Indigenous methodological approaches are not prescriptive, there is no single framework, however there are consistent principles and constructs which underpin Indigenous methodologies as outlined by Indigenous and Aboriginal and Torres Strait Islander scholars. These principles include relationality and relationships, respect for land, culture and community, partnership, reciprocity, self-determination and sovereignty (ownership and control). Indigenous methodology includes values and practices that Aboriginal and Torres Strait Islander people consider to be important such as relationality, partnerships, reciprocity, community driven priorities and fundamentally it is research that ultimately benefits communities (Dudgeon et al. 2020; Martin-Mirraboopa 2003; Moreton-Robinson 2013; Nakata 2002; Rigney 1999; Smith 2012; Wilson 2008). These methodological articulations have enabled the inclusion of Indigenous world views into Western methodologies supporting critique of Western methodologies and their suitability for Indigenous communities (Rigney 1999; Smith 2012; Wilson 2008).

The emergence of these methodologies in Western literature by Indigenous scholars coincided with the rise of ethical accountability in research. This came at a time where there were emerging challenges to dominant knowledge systems from social sciences, feminism and participatory approaches which offered alternative points of view and challenged prevailing and dominant discourses of biomedical frameworks and more broadly Western science (Bainbridge, Tsey, et al. 2015; Hunt 2013; Kendall et al. 2011; Mohamed et al. 2021). Throughout this period, structures emerged in health research which required more ethical, appropriate and responsive research with Indigenous communities (Dudgeon, Kelly & Walker 2010; Kendall et al. 2011; National Health and Medical Research Council 2018; Smith 2012; Wilson 2008).

In the current context there are a range of strategies in place which embed Indigenous knowledge as core principles to enhance research. Examples of these include:

- Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)
   Code of Ethics for Aboriginal and Torres Strait Islander Research (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020);
- Keeping research on track II: a companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities (National Health and Medical Research Council (NHMRC) 2018); and
- South Australian Aboriginal and Torres Strait Islander Health Research Accord (South Australian Health and Medical Research Institute 2014).

Whilst these are not presented as an Indigenous methodology explicitly, the principles from within these guidelines can inform an Indigenous methodology and provide a framework which is able to guide the implementation and application of Indigenous methodological principles into Aboriginal and Torres Strait Islander research contexts (Table 2.1).

Table 2.1: Aboriginal and Torres Strait Islander ethical research guidelines principles and alignment to Indigenous Methodologies

| Ethical Framework  | Principles   |
|--|--|
| AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research  | Indigenous self-determination Indigenous leadership Impact and value Sustainability and accountability       |
| Keeping research on track II: a companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: guidelines for researchers and stakeholders              | Spirit and Integrity Reciprocity Respect Equality Survival and Protection Responsibility                     |
| SA Aboriginal Health Research Accord: The South Australian Aboriginal and Torres Strait Islander community's expectations of how research with, for and by Aboriginal people should be developed and conducted | Priorities Involvement Partnership Respect Communication Reciprocity Ownership Control Knowledge Translation |

The responsibility of researchers to undertake research 'the right way' aligns well to an Indigenous methodology. Implementing these principles within the research design and approach enables them to be embedded throughout the research process, enhances accountability and ultimately contributes to the safety, wellbeing, self-determination and

sovereignty of Aboriginal and Torres Strait Islander communities. Ethical approval for this PhD program of work was received from the Aboriginal Health Research Ethics Committee (AHREC) approval number AHREC 04-18-791 as detailed in Appendix 2.1.

#### 2.2.1 Participatory approaches and governance

Participatory, collaborative and consumer driven research continues to gain momentum internationally (Cargo & Mercer 2008; Vaughn & Jacquez 2020). Participatory research is defined as an approach which includes collaboration, solutions from the bottom up (consumers) and empowerment (Cargo & Mercer 2008; Cornwall & Jewkes 1995). Participatory approaches emerged at a time of growing recognition of the importance of the involvement of consumers and stakeholders in the research process from design and implementation to translation (Cargo & Mercer 2008; Cornwall & Jewkes 1995; Vaughn & Jacquez 2020). The shift towards Indigenous research governance and methodologies has re-positioned Aboriginal and Torres Strait Islander researchers as leaders in being able to implement participatory, strengths-based research processes which are of benefit to communities (Bainbridge, Tsey, et al. 2015; Dudgeon et al. 2020; Hunt 2013; Mohamed et al. 2021). "Top down" approaches to governance which have typically been employed in research perpetuate power imbalances between the researcher and the researched (Duke et al. 2021).

Aboriginal and Torres Strait Islander governance emphasises the importance of relationality to people and place in order to address these power imbalances (Duke et al. 2021). Applying principles of Aboriginal and Torres Strait Islander governance continues to be challenging for research teams and projects which are located within non-Indigenous knowledge systems and research environments (Duke et al. 2021). Participatory approaches offer a means to forge space for these principles to align within these contexts (Cochran et al. 2008; Kendall et al. 2011). Indigenous researchers and researchers working with Indigenous communities have highlighted the suitability of participatory approaches and their synergies with Indigenous ways of knowing, being and doing (Cochran et al. 2008; Cox et al. 2014; Dudgeon et al. 2020; Kendall et al. 2011). This program of work embeds participatory approaches through Aboriginal and Torres Strait Islander governance.

#### 2.3 Study Context

"An understanding of context is essential to the Indigenous health stories that are written today" Juanita Sherwood (2013, p. 29)

#### 2.3.1 Wardliparingga Aboriginal Health Equity

This PhD program of work is implemented within Wardliparingga<sup>4</sup> Aboriginal Health Equity Theme (Wardliparingga), situated in the South Australian Health and Medical Research Institute (SAHMRI), on Kaurna land, Adelaide, South Australia. Consistent with an Indigenous methodology, the Researcher and two members of the supervisory team are part of and work with Indigenous communities (Dickson 2020; Redvers & Blondin 2020) and adhere to the ways of working defined by the South Australian Aboriginal and Torres Strait Islander community. Wardliparingga has a large program of work using Indigenous methodologies combined with methods drawn from population health, health systems and services research, and implementation science. Programs of research include cardiovascular disease, diabetes, healthy ageing, adolescent health, language reclamation and the social determinants of health (Pearson et al. 2019).

Wardliparingga research aligns with community priorities identified through an extensive consultation process. To determine these community priorities, in 2013-2015 Wardliparingga in partnership with the Aboriginal Health Council of South Australia (AHCSA) undertook the *Next Steps* research project (King & Brown 2015). The process involved literature reviews, audits of the Aboriginal Health Research Ethics Committee (AHREC) database, interviews with Aboriginal Community Controlled Health Organisations (ACCHO), Aboriginal Health Advisory Councils and the Aboriginal and Torres Strait Islander community.

The aim of *Next Steps* was to identify and prioritise the needs and interests of Aboriginal and Torres Strait Islander people for health and medical research (King & Brown 2015). Next steps highlighted specifically a priority area relating to social and emotional wellbeing including *trauma counselling*, what works and what is available as well as the cultural, social, and governmental determinants of health. Next Steps also highlighted

<sup>&</sup>lt;sup>4</sup> Wardliparingga means 'house river place' in Kaurna language and is also the term for the Milky Way reflected in the Karrawirraparri River which runs alongside the South Australian Health and Medical Research Institute. This name was given by Kaurna language and knowledge holders - Kaurna Warra Karrpanthi.

that research needed to embody partnerships, reciprocity and community priorities to ensure benefit to communities and for Aboriginal and Torres Strait Islander people to be involved in, govern and determine all aspects of the research process (King & Brown 2015).

The South Australian Aboriginal Health Research Accord (The Accord) (South Australian Health and Medical Research Institute 2014) introduced in the previous section of this chapter (section 2.2) has been pivotal to both Wardliparingga and the program of work outlined in this thesis. The Accord requires that research is designed in partnership with and benefits Aboriginal and Torres Strait Islander peoples and communities.



Figure 2.1 The South Australian Aboriginal Health Research Accord Principles

Adapted from the South Australian Health and Medical Research Institute 2014, 'South Australian Aboriginal Health Research Accord: companion document', South Australian Health and Medical Research Institute (SAHMRI), Adelaide.

The Accord was developed as a guide for doing research the right way and is informed by evidence of 'best practice' for conducting health research with Indigenous populations nationally and internationally (South Australian Health and Medical Research Institute 2014). Principles were refined through engagement with South Australian Aboriginal and Torres Strait Islander communities, health service providers, key stakeholders, researchers and academic staff across South Australian universities (South Australian Health and Medical Research Institute 2014).

The Accord is designed to be complementary to existing national statements and guidelines (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council (NHMRC) 2018), to set expectations, and provide accountability for high quality and culturally relevant research with South Australian Aboriginal and Torres Strait Islander communities (South Australian Health and Medical Research Institute 2014).

#### 2.3.2 Aboriginal and Torres Strait Islander population context

Australia is the sixth largest country and one of the least densely populated land masses in the world. However, Australia is highly urbanised with many people residing in major cities or inner regional areas (Australian Bureau of Statistics 2021a; Rickard 2017). Modern Australia is often described as a 'lucky country' with many freedoms and a diverse identity as a 'multi-cultural' society (Rickard 2017). Despite these common narratives, Australia has an international reputation for the unacceptable health outcomes experienced by Aboriginal and Torres Strait Islander communities, and especially those in remote communities (Australian Institute of Health and Welfare 2022b).

The Aboriginal and Torres Strait Islander population is estimated to be 649,171, which is 3.3% of the total Australian population, as at the 2016 Census (Australian Bureau of Statistics 2016c). In Australia remoteness is categorised as major cities, inner regional, outer regional, remote and very remote as outlined in Figure 2.2. There is a common narrative that Aboriginal and Torres Strait Islander people reside mostly in very remote areas, however it is estimated that 37% of the population live in major cities, 24% in inner regional, 19.7% in outer regional, 6.2% in remote and 12.2% in very remote areas (Australian Bureau of Statistics 2016c). There are 34,184 Aboriginal and Torres Strait Islander people living in South Australia representing 5.3% of the national Aboriginal

and Torres Strait Islander population. In South Australia, 51.9% of the Aboriginal and Torres Strait Islander people live in metropolitan areas, 10.7% in inner regional, 22% outer regional, 3.8% in remote and 10.8% in very remote areas (Australian Bureau of Statistics 2016c).

Australian Bureau of Statistics

2016 Australian Statistical Geography Standard: Remoteness Structure
Remoteness Area Boundaries

Remoteness Areas

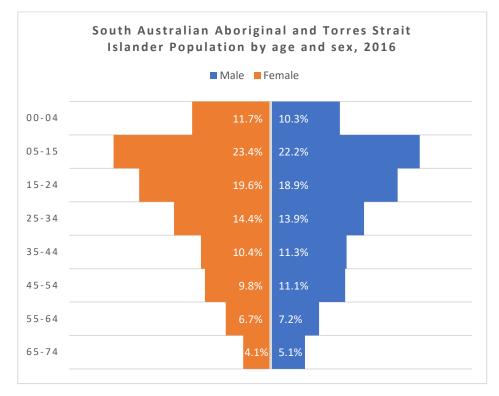
Major Cities of Australia
Inner Regional Australia
Outer Regional Australia
Remote Australia

Figure 2.2: Australian Remoteness Areas

Map sourced from the Australian Statistical Geography Standard (ASGS) Volume 5 – Remoteness Structure (cat. no. 1270.0.55.005)

The Aboriginal and Torres Strait Islander population has larger proportions of young people (0-25 years) and smaller proportions of older people (55+ years) than the non-Indigenous population (Figure 2.3).

Figure 2.3: Summary of the South Australian Aboriginal and Torres Strait Islander population, 2016



Data Source: Census population, by Aboriginal status, sex, and age, South Australia, 2016 sourced from South Australian Aboriginal Landscape Reports

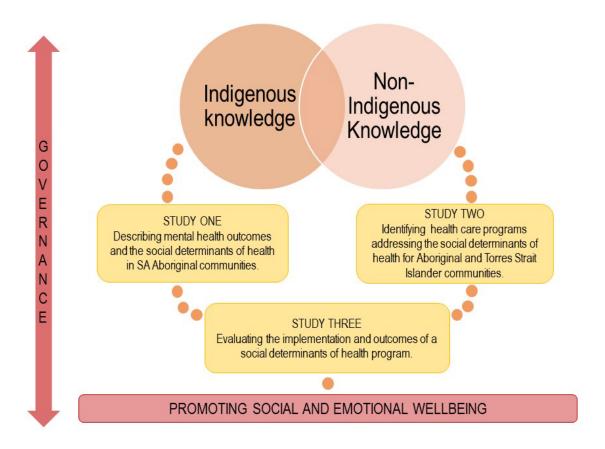
This population distribution is reflective of high mortality rates (Australian Bureau of Statistics 2016c) and the significant health and socio-economic inequities experienced by Aboriginal and Torres Strait Islander communities.

#### 2.4 Research Design Framework

"As Aboriginal researchers, we do not assume to be objective. We know there is no such thing." Larissa Behrendt in Archibald et al. (2019) p.185

Indigenous knowledges and methodology informed the research design framework outlined in Figure 2.4.

Figure 2.4: Research Design Framework



Iterative mixed methods are utilised to support emerging knowledge and understandings as part of the developmental approach to inform and enhance the research process (Chilisa & Tsheko 2014; Johnson, Onwuegbuzie & Turner 2007). The applied insider approach utilises and draws on the lived experiences of the researcher as an Aboriginal woman and the inter-disciplinary knowledge of the researcher. This includes disciplines of public health, implementation science and social work. Innately, insider approaches acknowledge the limitations of 'objectivity' and embrace 'subjectivity' as a strength. Being part of the same community or having the same lived experience can support engagement in the research process and the relationship between the researcher and research participants, with the researcher better able to understand and represent lived

experiences (Berger 2013; Kwame 2017; Ortlipp 2008). Self-reflection enables the researcher to monitor and mitigate any risks from the approach (Berger 2013; Drake 2010; Kwame 2017; Ortlipp 2008; Wilkinson & Kitzinger 2013), along with a range of structures from supervision to community engagement which provide an 'external' framework and structure to the approach.

The involvement of community and key stakeholders ensures the diversity of Aboriginal and Torres Strait Islander communities is represented and reflects local contexts such as cultural protocols, community demographics and needs which are specific to context, it also enhances accountability of the research process to the community (Duke et al. 2021; Harfield, Pearson, et al. 2020; Hunt 2013; King & Brown 2015; Laycock 2011; Mohamed et al. 2021; South Australian Health and Medical Research Institute 2014). As part of this research design framework the engagement of the community through participatory approaches is embedded in a governance structure. Evidence indicates that research which is reflective of community values, priorities and perspectives can contribute to more relevant and meaningful outputs for Aboriginal and Torres Strait Islander people with a greater potential for knowledge translation (Harfield et al. 2020).

#### 2.5 Methods

"Indigenous research Knowledges and methodologies have existed over millennia, however it is only recently that Indigenous scholars have been able to challenge institutional Western hegemony to reclaim sovereignty in the research space."

#### Ryder et al. (2020)

As outlined in the research design framework, this program applies iterative and mixed methods underpinned by the Indigenous methodology which informed the selection of theoretical approaches, methods and analytical techniques. The methods and key considerations across each of the studies are summarised in Table 2.2 and described in detail in *Section 2.7: Indigenous Methodology and Applied Methods*.

Table 2.2: Summary methods, analytical techniques, and data sources

|                               | Study 1: Explore variations in community level mental health and social determinants   | Study 2:<br>Identify health care<br>programs addressing<br>social determinants            | Study 3:<br>Evaluate a social<br>determinants of<br>health program  |
|-------------------------------|--|---|---|
| Indigenous<br>Methodology     | <ul><li>Self-determination</li><li>Data Sovereignty</li><li>Strengths-based epidemiology</li></ul>                                     | <ul><li>Partnership<br/>approach</li><li>Culturally relevant<br/>understandings</li></ul> | <ul><li>Participatory</li><li>Insider approaches</li><li>Culturally informed</li></ul>                          |
| Non-Indigenous<br>Methodology | Descriptive     Epidemiology   | <ul> <li>Scoping Review<br/>(Evidence<br/>Synthesis)</li> </ul>                           | Developmental<br>Evaluation   |
| Analytical<br>Technique       | Descriptive Analysis   | Descriptive     Analysis  | <ul> <li>Descriptive<br/>Analysis</li> <li>Qualitative<br/>Analysis</li> <li>Reflective<br/>Practice</li> </ul> |
| Data Source/s                 | Secondary Analysis<br>of administrative &<br>survey data held by<br>the South Australian<br>Aboriginal<br>Landscape Data<br>Repository | Data extracted<br>from included<br>programs   | Cultural     Pathways     Program Data  |

#### 2.6 Aboriginal and Torres Strait Islander Governance

"Regardless of the different contexts in which Indigenous people and researchers operate, there remains a cultural, political and ethical imperative to reposition Indigenous peoples from passive subjects of research to autonomous actors in health research governance." Bond, Foley and Askew (2016)

The following section provides further explanation of how the South Australian Aboriginal Health Research Accord (South Australian Health and Medical Research Institute 2014) principles (in bold text) are understood within the evidence, practical applications in research and how they are applied to this program of work.

The **involvement** of Aboriginal and Torres Strait Islander people and organisations in the development, implementation and translation of research is essential (South Australian Health and Medical Research Institute 2014). Consistent with Indigenous methodologies the focus should be on building relationships and respect by explicitly recognising the authority of Indigenous knowledges and custodianship of knowledge (South Australian Health and Medical Research Institute 2014). This is applied by adapting methodologies and methods to ensure they represent Aboriginal and Torres Strait Islander cultures and communities and are consistent with Aboriginal and Torres Strait Islander ways of knowing, being and doing (Martin-Mirraboopa 2003; Rowe, Baldry & Earles 2015) (Bainbridge, Tsey, et al. 2015; Cochran et al. 2008; Hunt 2013; South Australian Health and Medical Research Institute 2014). A partnership approach to research with Aboriginal and Torres Strait communities should be grounded in the establishment of mutual trust that enables Aboriginal and Torres Strait Islander people to have an integral role in research which effects their lives and communities (South Australian Health and Medical Research Institute 2014). Governance structures such as reference groups or advisory groups ensure that research addresses community priorities and ultimately ensures a greater benefit to community and impact of research with communities (Bainbridge et al. 2015; Hunt 2013; Mohamed et al. 2021).

The governance structure for this program of work included an Advisory Group. As per the Terms of Reference (Appendix 2.2), the aim of the Advisory Group was to provide advice and guidance on the program of work including implementation, interpretation of findings and recommendations for these findings to inform and influence health systems, policy and practice. The specific objectives of the group were to:

- Provide advice on the implementation of the PhD project studies,
- Guide the interpretation of findings and results,
- Identify recommendations based on the information gathered,
- Inform the development of a plan on how to distribute the information (knowledge exchange),
- Provide advice on the presentation of the information, and
- Provide advice and advocacy to inform policy/systems/practice changes.

Advisory Group membership included Indigenous knowledge and expertise and relevant industry expertise with representation across multiple sectors to capture the large scope of knowledge required.

- Aboriginal community members
- Aboriginal Health Council of South Australia (AHCSA)
- Council of Aboriginal Elders of South Australia
- SA Government Aboriginal Affairs (Aboriginal Affairs and Reconciliation Division)
- SA Health (Aboriginal Health Branch)
- Non-government social services (South Australian Council of Social Services)

The engagement with the Advisory Group throughout the implementation of the project was flexible with face-to-face meetings, one to one consultations or small focus groups occurring by negotiation with members depending on the needs and stages of the project. The flexible approach also included the invitation of topic experts to join the group in addition to, or in place of existing membership for specific projects or activities. Culturally relevant communication that utilises Aboriginal and Torres Strait Islander communication styles such as thoughtful, deep listening, thinking, reflecting and considering are processes which may take time (Bessarab & Ng'Andu 2010; Marriott et al. 2019; South Australian Health and Medical Research Institute 2014; West et al. 2013). This requires approaches which are flexible for the researcher to develop and maintain relationships with the community, key decision makers and leaders, throughout the entire

research cycle (South Australian Health and Medical Research Institute 2014). Implementing partnership approaches is not without challenges and the involvement and engagement of community members was not always successful throughout the duration of the research. The intent was for there to be community representation on the Advisory Group which was representative of community diversity in gender, age and varied lived experiences, however for this, and many projects, this was challenging to achieve. The engagement of community members in dual roles – for example as professionals with expertise in their respective fields as well as community leaders was able to balance out these limitations in this instance.

Aboriginal and Torres Strait Islander communities and services are frequently under resourced and overburdened with community members and leaders with large responsibilities and obligations – and as such research should not place pressure on or deplete the resources of communities. These factors contributed to challenges in the engagement of key stakeholder groups (Elders Council and AHCSA), potentially influenced by competing demands for these groups. Research with Aboriginal and Torres Strait Islander communities should deliver benefits to the community, determined by the community, in the spirit of reciprocity (Bainbridge, Tsey, et al. 2015; South Australian Health and Medical Research Institute 2014). Research benefits universities, institutions, and researchers in many ways and most importantly research should benefit communities (Bainbridge, Tsey, et al. 2015). This requires a balanced approach in considering the demands placed upon community, the ongoing wellbeing of community members and the needs of the project. Maintaining positive ongoing relationships may require a deviation from the initial engagement plan made in consultation and with the support of those involved. (National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014; Wand & Eades 2008).

An example of this was the COVID-19 pandemic which placed immense pressure on communities (Follent et al. 2021), and this project and the governance approach were not exempt from that. The need to prioritise community safety and the pressure and challenges placed upon those who agreed to participate in the Advisory Group for this project before COVID-19 significantly impacted their workload and commitments. A highly flexible approach was implemented with more online opportunities for engagement created to support completion of the program of work.

Remaining consistent with Indigenous ways of knowing, being and doing, grounded in relationships and flexibility can facilitate the engagement and reciprocity for all involved. The flexible engagement approaches described throughout this section were integrated into the three studies to enhance the meaning, understanding and interpretation of emerging findings to ensure relevance and responsiveness to the needs and priorities of the community. This also enabled an integrated and embedded approach to **knowledge translation** and the ability to plan for research findings to influence policy and practice.

#### 2.7 Indigenous Methodology and Applied Methods

"What happens to research when the researched become the researchers?"

Smith (2012, p. 186)

Indigenous methodologies are implemented in a range of ways throughout this program of work, the following section summarises the applied approaches in each study.

2.7.1: Self-determination, Data Sovereignty and Strengths-based epidemiology (Study 1) Chapter One highlighted that Aboriginal and Torres Strait Islander people have long been striving for sovereignty, rights and self-determination. When it comes to data, and data about Indigenous communities, in Australia and across the globe, there has been an absence and arguably an exclusion of an Indigenous presence in data produced about and for Indigenous populations (Walter & Suina 2019). This has resulted in deficit narratives which have focused on the problems of communities (Fogarty et al. 2018; Kukutai & Taylor 2016; Walter 2018; Walter et al. 2021). It is imperative that Aboriginal and Torres Strait Islander communities have ownership and control over Indigenous knowledge (South Australian Health and Medical Research Institute 2014), and that communities are able to shape the use of data and narratives about their own communities. The South Australian (SA) Aboriginal Health Landscape program (Landscapes) provides the platform to tell culturally safe and relevant stories and advocate for policy and practice changes (Pearson et al. 2019). Landscapes is underpinned by Aboriginal and Torres Strait Islander knowledges and takes a community empowerment approach to data governance and enables Aboriginal and Torres Strait Islander governance of health and social data and the reporting and monitoring of community level health and social outcomes (Pearson et al. 2019). The approach to Study 1 utilises descriptive epidemiology to better understand outcomes which have been identified as priority needs by the community (King & Brown 2015) and avoids problematising communities with a deficit narrative (Walter 2018) by focusing on how adverse outcomes are produced by unequal systems and structures. The PhD program Advisory Group as well as the Landscapes Governance Group were engaged at the beginning of the project for endorsement of the use of Landscapes data to explore mental health outcomes and the social determinants of health as part of the project and in the spirit of reciprocity are available to communities to support them to utilise the findings as they determine.

#### 2.7.2 Partnership approach for culturally relevant understandings (Study 2)

A scoping review supported being able to understand what was already being done and to learn from existing evidence. The scoping review method by Levac, Colquhoun and O'Brien (2010) is suited for peer reviewed and grey literature. The importance of adapting methodologies has been reiterated throughout this chapter. The approach undertaken in this study included enhancing the scoping review methodology to better align with Indigenous ways of knowing, being and doing. This included a collaborative partnership approach with the aim of achieving culturally relevant understandings which best reflect the current context and lived experiences (Cargo & Mercer 2008; Usher et al. 2021). The scoping review question and criteria were collaboratively designed with the Advisory Group and potential additional studies were identified through engagement with key experts and members of the Advisory Group. Each program included for data extraction was assessed from an Aboriginal and Torres Strait Islander perspective for cultural relevance and responsiveness using a culturally developed tool to appraise Aboriginal and Torres Strait Islander evidence within the literature. These are examples of embedded approaches which supported breadth and culturally relevant understanding so that the results could be utilised not only as part of this project but more broadly to support understandings on taking action on the social determinants of health. A detailed methods paper of this approach is outlined in Chapter 4.1.

#### 2.7.3 Participatory, insider approaches and culturally informed evaluation (Study 3)

A developmental evaluation supported innovation and adaptation and was consistent with approaches based on partnerships, trust and shared decision making (Patton 2010; Patton, McKegg & Wehipeihana 2015). As the Evaluator, TB worked with the team in real-time, asking evaluation questions, examining and tracking implications of adaptions and providing timely feedback (Patton 2010, 2016; Patton, McKegg & Wehipeihana 2015). The approach supported immersive, 'insider' perspectives and using these as a strength in the research process which was consistent with Indigenous methodology (Moreton-Robinson 2013; Patton 2010). Insider approaches are referenced across a range of disciplines including social work, feminist and participatory methods (Bainbridge et al. 2011; Kanuha 2000; Wilkinson & Kitzinger 2013). Through 'being on the inside' the researcher offers a cultural understanding and perspective which supports empowerment for both the researcher and the community, to ensure that knowledge and understandings

are consistent with Aboriginal and Torres Strait Islander ways of knowing, being and doing.

Insider research can be applied in a range of different ways with approaches described by Wilkinson and Kitzinger (2013) as minimising (ignoring personal experience); utilising (strategically as part of design and implementation); maximising (study ones own experience); and incorporating (including researcher as a research participant). The approach in this PhD program of work aligned with utilising strategically the Aboriginal researchers lived experience. An insider is more sensitised and familiar with the context and content, they know what and how to ask, and can better understand the nuances of responses and results (Berger 2013; Kwame 2017; Ortlipp 2008). Importantly, a great degree of self-awareness and self-reflection is required on the part of the researcher when engaged on 'the inside' (Berger 2013; Drake 2010; Kwame 2017; Ortlipp 2008; Wilkinson & Kitzinger 2013). Qualitative research theories define this as reflexivity; an active acknowledgement by the researcher of the role of self in the research process (Berger 2013; Kwame 2017; Ortlipp 2008). Reflexivity is used to account for the researchers' values, beliefs, knowledges and bias and is particularly critical when studying the familiar (Archibald et al. 2019; Bainbridge et al. 2011; Berger 2013; Kwame 2017; Ortlipp 2008).

The use and positioning of an insider approach to research is consistent with an Indigenous methodology in that it enables a close relationship to the research and as the findings emerge to inform an iterative, action research design which ultimately benefits communities and avoids contributing to narratives which have been used to control and disempower Aboriginal and Torres Strait Islander people in the past (Archibald et al. 2019; Bainbridge et al. 2011). The evaluation aimed to understand the process (what and how) for individuals, community, service provision and systems. Additionally, the difference the program made to Aboriginal and Torres Strait Islander peoples' social and emotional wellbeing. Participant yarns or semi-structured interviews ensured their voice was included to inform understandings of how effective the program had been. The Advisory Group were involved in informing the broader evaluation aims, interview questions with participants and interpreting the findings as well as providing input into the dissemination strategy. Engagement with the Advisory Group evolved over time and governance also included the Cultural Pathways Program staff and research team.

#### 2.8 Conclusion

Indigenous methodologies continue to grow in both understanding and uptake for Indigenous and non-Indigenous researchers nationally and internationally. An Indigenous methodology can ensure that research with Indigenous communities is culturally relevant and safe for the best outcomes and greatest benefit. Within the literature, applied approaches to Indigenous methodology are still emerging, however articulations of scholars and guidelines such as the South Australian Aboriginal Health Research Accord (South Australian Health and Medical Research Institute 2014) can provide a framework for an applied Indigenous methodology. Decolonising discourse has grown in use in recent years, however to genuinely undertake decolonising approaches requires a complete restructure, undoing and redoing anew, of the systems which oppress and disempower (Smith 2012). Achieving self-determination and sovereignty for Indigenous people in a colonial euro-centric society requires unravelling and challenging dominant discourses across systems and structures, Indigenous methodologies offer opportunities for progress in a research context (Smith 2012). The applied methodology of this PhD sits at the 'interface' of prioritising Indigenous knowledges, challenging dominant systems and structures and making adaptions to methods to align with Indigenous methodologies and to make them safe, appropriate and relevant.

The researcher's standpoint and 'insider' perspective as an Aboriginal woman is utilised as part of the methodology to enable cultural understandings and insights that are not always available to those on the outside. Through governance and engagement with the supervisory team, the researcher balances the position between being on the inside and high quality, ethical and effective research practice. Governance structures and partnership approaches which are embedded within this program of work provide applied examples of flexible, relevant and meaningful engagement of community and stakeholders in the research process. Additionally, the combination of multiple theoretical positions and disciplines, with the Indigenous methodology all create flexibility and structure for understanding the research questions within this program of work. Through the explicit articulation of the applied Indigenous methodology in this thesis, there is potential to strengthen research and contribute to sovereignty through high quality research that benefits communities. Cultural connections and knowledge are a strength of Indigenous researchers which contributes to self-determination and understandings which are by us and for us as Indigenous peoples.

#### **CHAPTER THREE:**

# GEOGRAPHIC VARIATIONS IN COMMUNITY LEVEL OUTCOMES FOR MENTAL HEALTH AND THE SOCIAL DETERMINANTS OF HEALTH

#### 3.1 Background

For Aboriginal and Torres Strait Islander people 'place' represents identity, connection and spirituality beyond physical spaces or geographic locations. Understandings of 'place' are shaped by geography, cultural experiences, colonisation, historical and political factors (Blignault & Williams 2017; Watkin Lui 2012). The disparities in health and social outcomes between the Aboriginal and Torres Strait Islander and non-Aboriginal population has been extensively documented in a plethora of reports, however such findings utilise administrative data collections that are expressed by government geographic boundaries which are not community defined (Australian Institute of Health and Welfare 2020a, 2021a; Commonwealth of Australia 2018a; Walter 2018). Data which describes the burden of disease and pervasive unmet health and social needs can support targeting resources where they are needed most and enable systems to monitor and improve health and social outcomes (Walter & Andersen 2013). How data are used and the stories they tell are representations of every-day experiences of Aboriginal and Torres Strait Islander communities (Walter & Andersen 2013). However, the way these stories have been told and the lens through which this data has been viewed often removes the human and lived experiences and focuses on deficits of Indigenous populations compared to non-Indigenous populations (Walter & Andersen 2013). In doing this, socioeconomic and health measures reported for non-Indigenous populations are presented as the "standard" while Indigenous population outcomes are reported as "problems or deficits" (Walter & Andersen 2013). The Aboriginal and Torres Strait Islander population is diverse with hundreds of language groups, specific cultural practices and social organisation, which are not well understood within and across geographical locations and current approaches to data collection often do not reflect the diversity of communities (Trudgett et al. 2022),.

In South Australia, a community project has adopted place-based approaches. The South Australian (SA) Aboriginal Landscapes Project ("Landscapes") is led by Wardliparingga Aboriginal Health Equity (Wardliparingga) Research Theme at the South Australian Health and Medical Research Institute (SAHMRI). This initiative reports population health and social outcome data at a small area level which includes 19 contiguous geographical units in South Australia, named "Landscapes" (Pearson et al. 2019). Landscapes aims to: 1) enable Aboriginal governance of Aboriginal health and social data, 2) report and monitor community level health and social outcomes of Aboriginal

people through an equity lens, and 3) to distribute and use the evidence generated to inform policy and practice changes.

Chapter Three will access the Landscapes data platform to explore associations between geographic variations in mental health outcomes and the social and determinants of health for South Australian Aboriginal and Torres Strait Islander communities. The findings will uniquely document unmet social needs in relation to community-level social determinants of mental health for Aboriginal and Torres Strait Islander people.

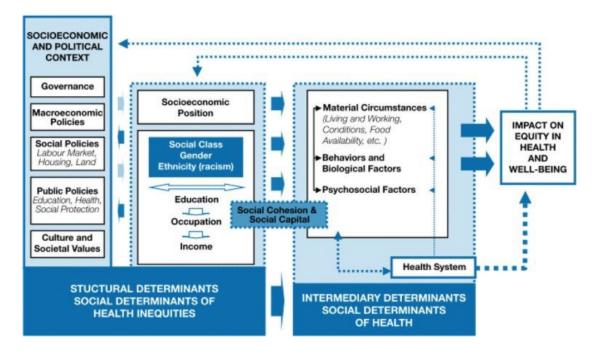
#### 3.1.1. Mental health and the social determinants of health

Connection to mind and emotions, specifically mental health, is an important domain of Aboriginal and Torres Strait Islander social and emotional wellbeing, as highlighted in Chapter One (Gee et al. 2014). In recognising this, this chapter focuses on mental health as a health outcome specifically and this terminology is used throughout the chapter. Mental health is defined as a state of wellbeing where a person has the skills and resources to navigate adversity, meet their needs and live a meaningful life (South Australian Mental Health Commission 2017; World Health Organization 2014). Mental health challenges are thoughts, feelings or behaviours which cause someone distress or impairment by impacting on mental health and wellbeing and may occur with or without diagnosed mental illness (South Australian Mental Health Commission 2017; World Health Organization 2014). Mental illness is a clinically diagnosable disorder that interferes with a person's cognitive, emotional or social abilities (South Australian Mental Health Commission 2017; World Health Organization 2014). For Aboriginal and Torres Strait Islander populations, as part of the 2018–19 National Aboriginal and Torres Strait Islander Health Survey an estimated 66% of people reported 'low or moderate' levels of psychological distress, while 31% reported 'high or very high' levels of distress. This equates to 97% of the population experiencing some form of distress (ABS 2020). Where people live and the services, amenities and environment all shape their health and wellbeing. Mental health is shaped by the complex environmental, social, economic, cultural and historical factors which have been outlined in Chapter One.

In 2008 the World Health Organisation (WHO) Commission on Social Determinants of Health released a report outlining the need for an international approach for action on the social determinants of health (WHO Commission on Social Determinants of Health 2008). This report was followed by a publication in *The Lancet* arguing for health equity

through action on the social determinants of health, highlighting the need for major changes in social policies, economic arrangements, and political action which empowers people and communities (Marmot et al. 2008). These two key pieces of work became the foundation for the next 10-15 years of focus on conceptualising social determinants of health and building a research agenda that aims to inform health and social service provision (Smith et al. 2018). To facilitate international action on the social determinants of health, the WHO released the *Conceptual Framework for Action on the Social Determinants of Health* (Solar & Irwin 2010) (Figure 3.1). This framework is one of the most widely accepted and utilised conceptualisations of the social determinants of health.

Figure 3.1: World Health Organisation Social Determinants of Health Conceptual Framework



Reprinted with permission from 'A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice)', Solar, O. and Irwin, A. Page 6, Copyright 2010.

As depicted in Figure 3.1 social, political, cultural and structural determinants all contribute to and are shaped by socio-economic factors (Alderwick & Gottlieb 2019). There is a tendency in research and policy to conflate the aforementioned factors as social determinants, contributing to confusion and complicating the identification of potential mechanisms to take action (Alderwick & Gottlieb 2019). Socio-economic measures have commonly been used internationally and in Australia to operationalise social and economic factors which are often referred to as the social determinants of health (Shavers

2007). Socio-economic measures are utilised in health care research as an attempt to capture the resources required to achieve and maintain good health (Shavers 2007). To implement multi-level health and social system approaches that take action on the social determinants of health in order to promote social and emotional wellbeing requires access to social determinants of health data. Consistent with an increasing assertion of rights to Indigenous data sovereignty, understandings should be informed by local experiences and contexts.

# 3.1.2 Frameworks guiding measurement of social determinants of health and mental health outcomes

This thesis predominantly utilises the *Aboriginal and Torres Strait Islander Health Performance Framework* (Australian Institute of Health and Welfare 2020a) domains for the social determinants of health. Established by the Australian Government in 2006, the Health Performance Framework reports were designed with Aboriginal and Torres Strait Islander stakeholder consultation to provide measures for Indigenous Australians' health outcomes, key drivers of health and the performance of the health system (Australian Institute of Health and Welfare 2020a). The Health Performance Framework is intended to promote whole of government approaches to health and promote accountability for health outcomes (Australian Institute of Health and Welfare 2020a).

The structure of the Health Performance Framework has parallels with social and emotional wellbeing and aligns with the health and wellbeing concepts presented in this thesis including education (literacy and numeracy), employment and income. These factors align with international conceptualisation of key social determinants of health (Figure 3.1) (Alderwick & Gottlieb 2019; Australian Institute of Health and Welfare 2020a; Solar & Irwin 2010). Despite calls to action for the social determinants of health, public health approaches have largely remained focused on individual behaviours, such as smoking and diet, which while contributing to health inequities these alone disregard the drivers of such behaviours, or the causes of the causes (Marmot & Allen 2014). Health behaviours and person-related factors are articulated as determinants of health, however the relationship between social factors and health behaviours is bi-directional and existing evidence cautions against conflating behavioural and social risks (Alderwick & Gottlieb 2019). For this reason, health behaviours and person related factors are not included as social determinants of health throughout this thesis.

This section has highlighted multiple complexities for conceptualising the social determinants of health. The framing of social determinants of health throughout this thesis is adapted depending on the study, the available data, and consistency with Indigenous knowledge and understandings. This thesis has outlined a consistent approach in conceptualising the social determinants of health and the Health Performance Framework domains provide a framework to support this.

# 3.1.3 Data Collections for Aboriginal and Torres Strait Islander people

In Australia there are a range of ways in which data are collected *about* Aboriginal and Torres Strait Islander people. There are three primary sources of population data including: 1) Census data, 2) surveys and 3) administrative data. The Australian Bureau of Statistics (ABS) implements the Census of Population and Housing, which collects a range of demographic and socio-economic information of the entire population. In addition to Census, the ABS also implement specific surveys for targeted populations, such as the National Aboriginal and Torres Strait Islander Health Survey. Administrative data are predominantly collected by states and territories as part of the provision of services, for example demographic information for consumers and the types of services provided (Biddle 2014a). Approaches to Aboriginal and Torres Strait Islander data collection have changed over time (Biddle 2014a). There has been an extensive critique of the ways Aboriginal and Torres Strait Islander communities have been represented in data (Biddle 2014a; Griffiths et al. 2019; Trudgett et al. 2022; Walter 2016; Walter 2018; Walter et al. 2021; Walter & Suina 2019). However, complexity remains in relation to data sources, availability, ownership and sovereignty. There is a need for a different approach, grounded in Indigenous knowledges which focus on the strengths and resilience of Aboriginal and Torres Strait Islander communities.

Indigenous data sovereignty outlines the right of Indigenous peoples in relation to the collection, ownership and use of data about them, their lived experiences, and their lands and waters (Kukutai & Taylor 2016; Walter et al. 2021). Collection of data about Indigenous people has primarily been as part of government requirements or surveillance, rather than defined by and for the needs of Indigenous peoples (Kukutai & Taylor 2016). Data sovereignty supports Indigenous communities in their right to self-determination by ensuring that statistical frameworks and collections are culturally relevant and reflect world views. In doing so, this will promote participation in data collection, processes and governance and enable communities or populations to utilise their own data for their

advancement and development (Kukutai & Taylor 2016). There is little doubt that Aboriginal and Torres Strait Islander people must have sovereignty over what, how and why data are collected and the stories which are told with their data. This chapter aligns the importance of place-based stories to explore the association between geographic variations in mental health outcomes and the social and cultural determinants of health for South Australian Aboriginal and Torres Strait Islander communities.

## 3.2 Method

Observational epidemiology involves describing, measuring and analysing relationships between health status and other variables. A descriptive study outlines health status using routinely available data, such as administrative and Census data, and are often the first step in an epidemiological investigation (Bonita 2006). Descriptive studies do not attempt to analyse the link between exposure and effect and usually explore patterns by specific characteristics (Bonita 2006). In this chapter descriptive methods are used to detail placebased understandings on mental health outcomes and key measures that are constructs representing the social determinants of health. Ecological approaches are used to look at relationships or correlations where the unit of analysis is for groups or populations rather than individuals and where data has been collected for other purposes (Bonita 2006). In this Chapter, an ecological approach aggregates data from individuals to the community level to explore associations between mental health outcomes and social factors (determinants of health) across South Australian Aboriginal communities. This study has ethical approval from the Aboriginal Health Research Ethics Committee [AHREC 04-18-791] (Appendix 2.1) and through the South Australian Aboriginal Landscapes Project [AHREC 04-13-546].

# **Population**

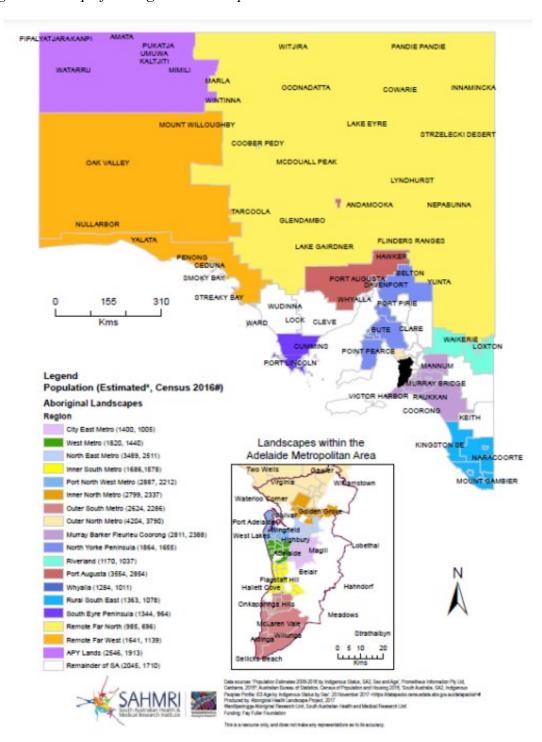
The population for this study are South Australian Aboriginal and Torres Strait Islander people as part of Landscapes, and is drawn from the 2016 Australian Bureau of Statistics (ABS) Census of Population and Housing. Data utilised within this Chapter were sourced from the South Australian Aboriginal Landscapes data platform.

# Landscapes

The Landscape Project divided South Australia into 19 discrete geographical areas termed 'Landscapes'. These Landscapes were developed to show where Aboriginal and Torres Strait Islander people live, as opposed to administrative boundaries, to better represent community groups (Pearson et al. 2019). These groups have large enough Aboriginal and Torres Strait Islander populations to present statistically sound results and concord with a common identifier within datasets, such as postcode (Pearson et al. 2019).

During development, Landscapes were presented to the Aboriginal Governance Group, two Wardliparingga Aboriginal Reference Groups and the Technical Panel to ensure meaningfulness to the community and statistical robustness (Pearson et al. 2019). Any recommendations were made resulting in the creation of Landscapes that cover South Australia (Pearson et al. 2019). The map in Figure 3.2 outlines the boundaries for each of the Landscapes.

Figure 3.2: Map of Aboriginal Landscapes



## 3.2.1 Mental Health Outcome

The diagnosis of mental illness is generally made according to the classification systems of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association 2013) and/or the International Classification of Diseases (ICD-10) (World Health Organization 2004). There are different types of mental illness, and they occur with varying degrees of severity. Examples include anxiety disorders, depression, bipolar disorder, eating disorders, and schizophrenia. This study was not focused on one specific disorder and therefore included the majority of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association 2013) and/or the International Classification of Diseases (ICD-10) (World Health Organization 2004) identified mental illnesses or disorders (Table 3.1). Psychological disorders which were not relevant to mental health conditions were excluded, these include disability (intellectual), aging (dementia/Alzheimer's) and children/adolescents (<15yrs not included population).

Table 3.1: Summary of International Classification of Diseases 10\_Australian Modification (ICD 10\_AM) codes and conditions: Chapter V Mental and behavioural disorders

| Code        | Description   | Summary  |  |  |  |
|-------------|---|--|--|--|--|
| F10-<br>F19 | Mental and behavioural disorders due to psychoactive substance use                                | Disorders attributable to the use of psychoactive substances includes dependence/addiction, withdrawal, psychotic episodes (drug induced psychosis etc)  |  |  |  |
| F20-<br>F29 | Schizophrenia,<br>schizotypal and<br>delusional disorders   | Continuous or episodic distortions of thinking and perceptions including hallucinations and paranoia.  |  |  |  |
| F30-<br>F39 | Mood [affective]<br>disorders   | Change in affect or mood to depression (with or without anxiety) or to elation. Includes mania, bipolar, depressive episodes and disorders.  |  |  |  |
| F40-<br>F49 | Neurotic, stress-related and somatoform disorders   | Includes anxiety disorders from phobic (agoraphobia, social phobia), panic disorder, generalised anxiety, mixed anxiety and depressive disorder, OCD, reaction to stress such as post-traumatic stress or adjustment disorders as part of an event (grief, illnesses, culture shock). Dissociative disorders - loss of integration between past, identity, sensations, body. Somatoform are often physical symptoms with requests for medical investigations e.g. hypochondriacal disorder |  |  |  |
| F50-<br>F59 | Behavioural syndromes<br>associated with<br>physiological<br>disturbances and<br>physical factors | Disorders which include disturbances physiologically and include physical factors such as eating disorders, sleep disorders not associated with other disorders, abuse of non dependence substances (such as paracetamol, laxatives etc).  |  |  |  |
| F60-<br>F69 | Disorders of adult personality and behaviour  | Conditions and behaviour patterns of clinical significance which tend to be persistent and appear to be the expression of the individual's characteristic lifestyle and mode of relating to himself or herself and others. Some of these conditions and patterns of  |  |  |  |

| significant deviations from the way in which the average individual in a given culture perceives, thinks, feels and, particularly, relates to others. |  | individual in a given culture perceives, thinks, feels and, |
|---|--|---|
|---|--|---|

# 3.2.2 Social Determinant of Health Exposure Variables

The Aboriginal and Torres Strait Islander Health Performance Framework (Australian Institute of Health and Welfare 2020a) provides the latest information across a range of health status and outcomes, determinants of health, and health systems performance measures. The Health Performance Framework includes measures developed in consultation with community and explicitly structures the determinants of health within the framework (Table 3.2). To support a more culturally aligned conceptualisation, this program of work utilises Health Performance Framework measures depicted in bold, as a guide for conceptualising the social determinants of health. These include education, employment, housing and income. Community capacities are reframed as cultural determinants for family and community connection, and connection to Country.

Table 3.2: Health Performance Framework: Determinants of health

| Determinant of Health       | Included Domains   |  |
|-----------------------------|--|--|
| Environmental               | Housing, Access to functional housing,                         |  |
|                             | Environmental Tobacco Smoke                                    |  |
| Socio-Economic              | Education outcomes and participation,                          |  |
|                             | employment, income, index of disadvantage and                  |  |
|                             | literacy and numeracy  |  |
| <b>Community Capacities</b> | Community safety, contact with the criminal                    |  |
|                             | justice system, <b>child protection</b> , <b>transport</b> and |  |
|                             | access to traditional lands                                    |  |
| Health Behaviours           | Tobacco use, risky alcohol consumption,                        |  |
|                             | substance use, physical activity, dietary                      |  |
|                             | behaviour, pregnancy and breastfeeding                         |  |
| Person Related              | Overweight and obesity   |  |

To date, Census data integrated within the SA Aboriginal Health Landscape project comprises expression of the following domains at the Landscape geographic unit including: Education, Employment, Housing and Income.

## Education

Education can contribute to a "decent standard of living" and educational attainment of Year 12 is considered to be an enabler in achieving that standard (Callander et al. 2012). For this reason, the education variable is utilised to focus on attainment as the *proportion of Aboriginal and Torres Strait Islander people who completed Year 12 or equivalent.* 

# **Employment**

Understandings of employment status of Aboriginal and Torres Strait Islander people are usually informed by employment data accessed through the Census. Census reports on employment status including the *proportion of Aboriginal and Torres Strait Islander people who are employed*.

## Housing

Available Census data in relation to housing captures dwelling or tenure types. Therefore, Census data has been utilised to report *Aboriginal and Torres Strait Islander Households with Secure Housing (buying, rented or public housing).* 

#### Income

As part of the Census, income is collected based on the household and can include income as wages and/or salaries from employment or from government pensions and allowances. *Poverty Lines* reports the minimum income levels required to avoid poverty for a range of family sizes and circumstances (Melbourne Institute of Applied Economic and Social Research ). In 2016, the estimated minimum household wage was \$900 for a family and/or \$700 for a single parent. This means to be above the poverty line in 2016, the year of the Census, a household income needed to equate to <\$900. To align this as closely as possible to income categories collected by Census, an above/below income category for households of \$999 per week was utilised and expressed as a *proportion of Aboriginal and/or Torres Strait Islander households with an income* <\$1000.

## 3.2.3 Data source considerations

#### Census

The Census is implemented by the ABS every five years and collects a range of demographic and socioeconomic information of the entire population. Individuals participate in the Census by completing the paper or online forms, and in some areas visits are made to households (Australian Bureau of Statistics 2016c). The Census includes

questions about age, country of birth, religion, ancestry, language used at home, work and education. The Census is the only available data source which can provide this information for the entire country, specific geographic areas and small population groups (Australian Bureau of Statistics 2016c). Prior to the 1967 referendum, Aboriginal and Torres Strait Islander people were excluded from the Census, meaning that until 1971 data had been collected with the purpose of exclusion rather than inclusion (Griffiths et al. 2019). From 1971 the self-identification question was introduced into the Census which enabled the identification of Aboriginal and Torres Strait Islander people as part of data collections (Griffiths et al. 2019).

Aboriginal and Torres Strait Islander participation in the Census is influenced by a range of factors, for example the approach of self-completion can contribute to lower engagement (Mahoney 2017). There have been significant increases (up 163,557 from 2016 to 2021) in people who identified as Aboriginal and/or Torres Strait Islander as part of the Census (Australian Bureau of Statistics 2021b). Proportions of these increases are explained by new births and parents who may be identifying children or movement in and out of the population (Australian Bureau of Statistics 2021b). Whilst other changes are attributed to self-identification and coverage responses, this includes more people completing the Census (Australian Bureau of Statistics 2021b). The ABS estimates that there are approximately 170,752 persons (rate of 17.4%) who should have been counted in the 2021 Census and were not (Australian Bureau of Statistics 2021b). Whilst the ABS has increasingly implemented approaches to engage Aboriginal and Torres Strait Islander communities in the Census, there is still considered to be low participation, resulting in under-reporting in Census data.

### Administrative Data

There are a range of systems utilised by states and territories as part of providing services which collect various types of data including the intervention, outcome and demographic information (Biddle 2014a; Department for Health and Wellbeing 2022). The Admitted Patient Care (APC)<sup>5</sup> records demographic, administrative and clinical data about patients separated (admitted and then discharged) from public and private hospitals in South Australia (Department for Health and Wellbeing 2022). The Admitted Patient Care (APC)

<sup>&</sup>lt;sup>5</sup> Formerly known as the Integrated South Australian Integrated Activity Collection (ISAAC).

provides SA Health with information to inform necessary resources to effectively plan and administer health services in South Australia (Department for Health and Wellbeing 2022). Mental health data are collected from all public hospitals and agencies that provide mental health services to the community with mental health information collected for children and adolescents, older people, and the rest of the adult population (Department for Health and Wellbeing 2022). In South Australia, mental health data from public administrative collections is collated and compared nationally to inform mental health care funding for service provision (SA Health 2022). Hospitalisations are the most consistent outcome measure used for mental health (Burns 2007). However, there is a wide variability in administrative data collection processes, particularly regarding the identification of Aboriginal and Torres Strait Islander people in administrative data collections (Mahoney 2017).

# Indigenous Status

Indigenous Status is used as a measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. Administrative data has many limitations around the reporting of Indigenous status with hospitals not always having appropriate processes and procedures in place to enable self-identification of Indigenous status (Mahoney 2017). Additionally, many Aboriginal and Torres Strait Islander people choose not to self-identify because they do not want it to adversely affect the care they receive (Mahoney 2017). This has significant implications for interpretations made from administrative data in terms of the potential to inaccurately represent the population (Griffiths et al. 2019). Reporting Indigenous status has also been noted as a significant limitation of Census data (Mahoney 2017). Mahoney (2017) highlights that the use of data to perpetuate disadvantage and contribute to negative discourses continues to contribute to low engagement of Aboriginal and Torres Strait Islander people in Census and surveys.

# 3.2.4 Summary of Variables

Variables for this study are summarised below in Table 3.3

Table 3.3: Summary of mental health and social determinant of health variable descriptions

| Domain             | Description  | Expression   | Period        | Data Source  |  |
|--------------------|--|--|---------------|--|--|
| <u>Outcome</u>     |  |  |               |  |  |
| Mental health      | a) Public Hospitalisation for mental and behavioural disorders     b) Emergency department presentation for mental and behavioural disorders     Place of residence (Landscape). | Area level<br>(Landscape<br>Geographic<br>units) rate<br>per 1,000   | 2011-<br>2018 | Admitted Patient<br>Care (APC), SA<br>Department of<br>Health and Aging    |  |
| <u>Exposures</u>   |  |  |               |  |  |
| Education          | Proportion of Aboriginal and Torres<br>Strait Islander People who completed<br>Year 12.  | % people<br>>15yrs   | 2016          | Census of<br>Population and<br>Housing, Australian<br>Bureau of Statistics |  |
| Employment         | Proportion of Aboriginal and Torres<br>Strait Islander People who are<br>employed.   | % people >15yrs#   |               |  |  |
| Housing            | Aboriginal and Torres Strait Islander<br>Households with <i>Secure Housing</i><br>(buying, rented or public housing).  | %<br>Households#   |               |  |  |
| Income             | Aboriginal and Torres Strait Islander<br>Households Weekly equivalised<br>household income greater than \$1,000  | %<br>Households#   |               |  |  |
| <u>Denominator</u> |  |  |               |  |  |
| Population         | Average Population (2011-2016)   | Aboriginal<br>and Torres<br>Strait<br>Islander<br>Persons<br>>15yrs# | 2011-<br>2016 | Census of<br>Population and<br>Housing, Australian<br>Bureau of Statistics |  |

Geographic Unit: # Landscape; APC: Admitted Patient Care.

## 3.2.5 Analysis

Descriptive analysis included the count of presentations presented by Landscape and mental health service type presentations, that is; 1) hospitalisation, and 2) emergency department. Mental health rates were calculated by Landscape count of hospital presentations for a mental health condition. The Landscape population (denominator) were drawn from the Aboriginal and Torres Strait Islander total population for each Landscape. The total population for each Landscape was used to calculate a median population for every Landscape (2011 and 2016 Census of Population and Housing, Australian Bureau of Statistics) and rate per 1,000 for mental health public hospitalisations and emergency department presentations.

Analysis included area-level (i.e., Landscape) exposures of Education, Income, Employment and Housing. The datasets for mental health are not linked, and therefore presented by service type (Hospitalisation, Emergency Department) for interpretation. Landscapes were grouped by a) urban b) regional and c) remote areas for contextual interpretation. Analysis was undertaken using Microsoft Excel for Windows 365 (Microsoft Corporation 2022a) and the analysis table is attached in Appendix 3.1.

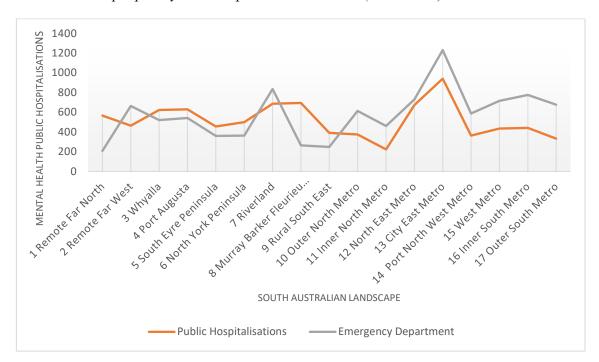
# 3.3 Results

# 3.3.1 Mental Health Hospitalisation Rates

In the period 2011-2017, City East Metro and Riverland Aboriginal and Torres Strait Islander residents had the highest rate of public hospitalisations and emergency department presentations for mental health. Aboriginal and Torres Strait Islander residents in City East Metro had a public hospitalisation rate of 1231 per 1000 population and emergency department presentations were 941 per 1000 population. In the Riverland the public hospitalisation rate for mental health was 687 per 1000 population and emergency department presentations were 836 per 1000 population.

Public hospitalisation rates were lowest for Aboriginal people residing in Inner North Metro (223 per 1000 population) and Outer South Metro (333 per 1000 population). Emergency department presentations rates were lowest among Aboriginal residents in Remote Far North (208 per 1000 population) and Rural South-East (248 per 1000 population). Among Murray Barker Fleurieu Coorong Aboriginal and Torres Strait Islander residents there were high rates of public hospitalisations for mental health (694 per 1000 thousand) but one of the lowest emergency department presentation rates (264 per 1000 population). Rural South East was the only Landscape where Aboriginal residents had low rates of public hospitalisation and emergency department presentations.

Figure 3.3: Mental Health Public Hospitalisations per 1,000 Aboriginal and Torres Strait Islander people, by Landscape, South Australia (2011-2018)



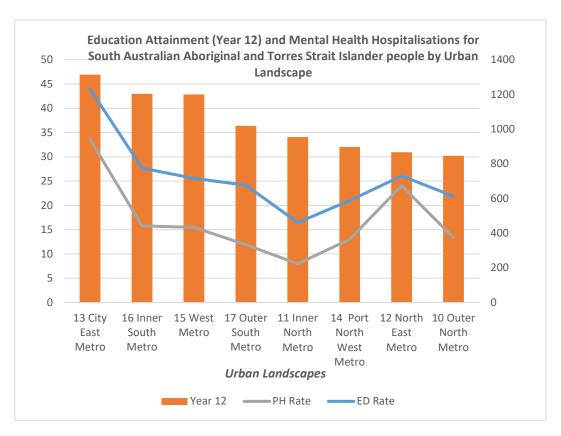
#### Notes:

- 1.Rate Calculation by dividing the Denominator (Average Landscape population for period 2011-2016) by 1,000 and then dividing the total hospitalisations by that figure. Sourced from Landscape Report Chapter 2: Population Context, Table 2.5.1. to calculate the average population 2011-2016
- 2.Public Hospitalisations: Rate of Public Hospitalisations for mental and behavioural disorders (ICD\_10\_AM Chapter V) per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing
- 3.Emergency Department Presentation: Rate of Emergency Department Presentations for mental and behavioural disorders (ICD\_10\_AM Chapter V) per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing

## 3.3.2 Education

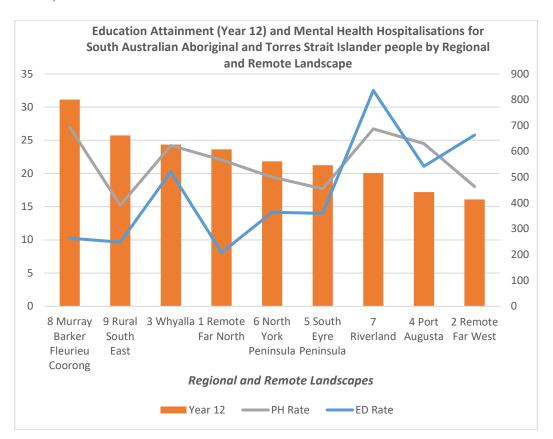
As at the 2016 Census, Aboriginal and Torres Strait Islander people living in the City East Metro Landscape had the highest proportion of year 12 attainment at 46.9% and the highest rate of hospitalisations for mental health among all Aboriginal and Torres Strait Islander people residing in urban areas (Figure 3.4). This was followed by Aboriginal residents in Inner South Metro (43.0%) and West Metro with 42.8% of the population reporting Year 12 attainment or equivalent. The lowest proportions of Aboriginal and Torres Strait Islander residents to report Year 12 attainment or equivalent resided in North-East Metro (30.9%) and Outer North Metro (30.2%). Within these Landscapes there were no discernible patterns between the mental health hospitalisation rate and proportion of the population with year 12 attainment or equivalent.

Figure 3.4: Education Attainment (Year 12) and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by urban Landscape, South Australia, 2011-2018



Lower proportions of Aboriginal and Torres Strait Islander people living in regional and remote area Landscapes reported Year 12 attainment compared to those living in urban Landscapes. The lowest proportions of year 12 attainment were reported by the Aboriginal and Torres Strait Islander population in the Riverland (20.0%), Port Augusta (17.2%) and Remote Far West (16.0%). A pattern emerged, showing an increase in hospitalisations and emergency department presentations in those Landscapes where 20% or less of the Aboriginal and Torres Strait Islander population reported Year 12 attainment or equivalent (Figure 3.5). Emergency department presentations were lower in regional Landscapes with higher proportions of people reporting Year 12 attainment (Murray Barker Fleurieu Coorong 31.1% and Rural South East 25.7%).

Figure 3.5: Education Attainment (Year 12) and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by regional and remote Landscapes, South Australia, 2011-2018



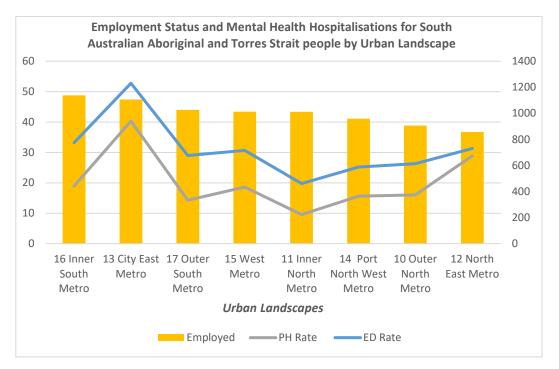
#### Notes:

- 1. PH Rate: Rate of Public Hospitalisations per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing
- 2. ED Rate: Rate of Emergency Department presentations per 1,000 for the place of residence (Landscape) at time of presentation. Data Source: ISAAC, SA Department of Health and Ageing
- 3. Education Attainment: Highest year of school completed for those >15yrs by place of residence (Landscape) as at 2016 Census. Data Source: South Australian Aboriginal Landscape Reports, Census data sourced from Australian Bureau of Statistics, 2016 Census of Population and Housing, South Australia, Indigenous Profile, downloaded November 2017.
  - Includes persons aged 15 years and over who are no longer attending either primary or secondary school.
  - 'Year 12 or equivalent' refers to people who have been awarded a statement or certificate of completion of year 12 by an Australian Government studies authority, and/or attained a Qualification at AQF Certificate Level II or above.
  - · Estimates have not been age standardised.
  - Cells and continuous variables in the underlying data have been randomly adjusted by the ABS to avoid the release of confidential data. Discrepancies may occur between sums of the component items and totals.

# 3.3.3 Employment

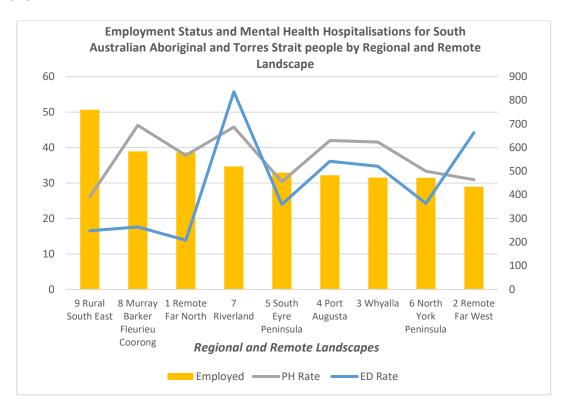
Employment status of the Aboriginal and Torres Strait Islander population in all urban Landscapes was below 50% (Figure 3.6). The Inner South Landscape population had the highest employment rate (48.8% employed) and a similar rate of mental health hospitalisations (442 per 1,000 population) as the North-East Metro population (674 per 1,000 population) who had the lowest rate of employment (36.7% employed). City East Metro population had the second highest rate of employment (47.3%) and the highest mental health hospitalisation rate (941 per 1,000 population).

Figure 3.6: Employment Status and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by urban Landscapes, South Australia, 2011-2018



Employment rates among the Aboriginal and Torres Strait Islander population in regional and remote Landscapes was lower than urban areas with the exception of Rural South East which had the highest rate of employment (50.6%) across South Australia and the lowest rate of mental health hospitalisation (391 per 1,000 population) (Figure 3.7). Emergency department presentations were lower for populations in Landscapes with higher rates of employment including Murray Barker Fleurieu Coorong (264 per 1,000 population, 38.9% employment) and Remote Far North (208 per 1,000 population, 38.6% employment). Rate of public hospitalisations for mental health for Aboriginal and Torres Strait Islander people were similar between regional and remote Landscapes with higher or lower proportions of the population in employment.

Figure 3.7: Employment Status and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by regional and remote Landscape, South Australia, 2011-2018



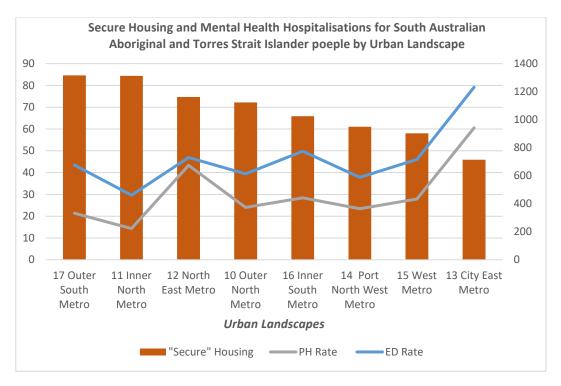
#### Notes

- 1. PH Rate: Rate of Public Hospitalisations per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing
- 2. ED Rate: Rate of Emergency Department presentations per 1,000 for the place of residence (Landscape) at time of presentation. Data Source: ISAAC, SA Department of Health and Ageing
- 3. Proportion of Aboriginal and Torres Strait Islander People >15 years who are employed, by place of residence (Landscape) as at 2016 Census. Data Source: South Australian Aboriginal Landscape Reports, Census data sourced from Australian Bureau of Statistics, 2016 Census of Population and Housing, South Australia, Indigenous Profile, downloaded November 2017.
  - Cells and continuous variables in the underlying data have been randomly adjusted by the ABS to avoid the release of confidential data. Discrepancies may occur between sums of the component items and totals.

# 3.3.4 Housing

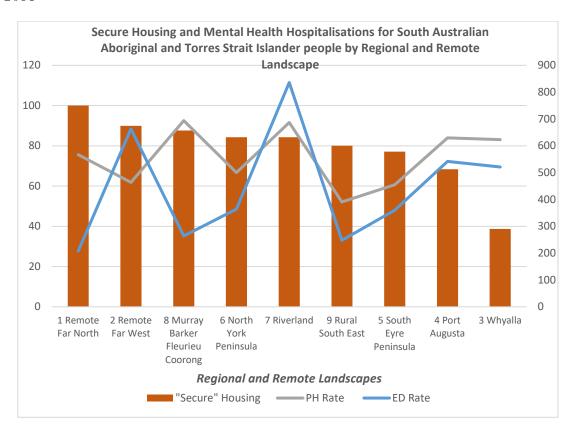
In urban Landscapes, mental health emergency department presentations and public hospitalisation rates for Aboriginal and Torres Strait Islander people were lower in those Landscapes with higher proportions (>80%) of households in secure (own, renting, or buying) housing including; Outer South Metro (84.6%) and Inner North Metro (84.4%) (Figure 3.8). Aboriginal and Torres Strait Islander people living in City East Metro had the highest rates of emergency department presentations (1231 per 1,000 population) and public hospitalisations for mental health (941 per 1,000 population) and the lowest proportion of households with secure housing (45.9%) among all urban Landscapes.

Figure 3.8: Secure Housing and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by urban Landscape, South Australia, 2011-2018



Regional and Remote Landscapes comprised of a higher proportion of Aboriginal and Torres Strait Islander households in secure housing compared to urban areas. Remote Far North had the highest rate of secure housing (100%) and emergency department presentations were lower (208 per 1,000 population), similar to Murray Barker Fleurieu Coorong (264 per 1,000 population emergency presentations, 87.6% secure housing) (Figure 3.9). Remote Far West Aboriginal and Torres Strait Islander population had a high secure housing rate (89.9%) and a high rate of hospitalisations for mental health. In regional and remote Landscapes, those with the lowest rate of secure housing, including Whyalla (38.7%), did not have higher hospitalisations compared to other Landscapes with higher proportions of households with secure housing.

Figure 3.9: Secure Housing and Mental Health Hospitalisations for Aboriginal and Torres Strait Islander people by regional and remote Landscape, South Australia, 2011-2018



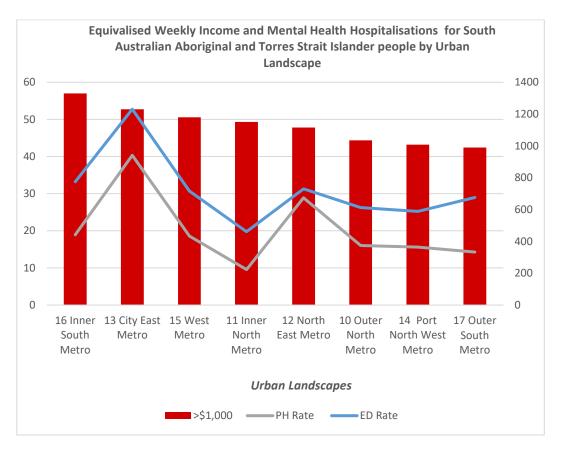
#### Notes

- 1. PH Rate: Rate of Public Hospitalisations per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing
- 2. ED Rate: Rate of Emergency Department presentations per 1,000 for the place of residence (Landscape) at time of presentation. Data Source: ISAAC, SA Department of Health and Ageing
- 3. Housing Status: Aboriginal and Torres Strait Islander Households with Secure Housing (owned, rented or public housing) by place of residence (Landscape) as at 2016 Census. Data Source: South Australian Aboriginal Landscape Reports. Census data sourced from Australian Bureau of Statistics, 2016 Census of Population and Housing, South Australia, Indigenous Profile, downloaded November 2017.
  - Includes occupied private dwellings only. "House' could include a separate house, a semidetached, row or terrace, townhouse, etc, or a flat or apartment.
  - 'Owning' could include owning outright or having a mortgage. 'Rented privately' includes renting through a real estate agent, renting from a person not in the household, another landlord type, or landlord not stated. 'Rented publicly' includes through a state or territory housing authority, a housing co-operative, or a community or church group.
  - Cells and continuous variables in the underlying data have been randomly adjusted by the ABS to avoid the release of confidential data. Discrepancies may occur between sums of the component items and totals.

## 3.3.5 *Income*

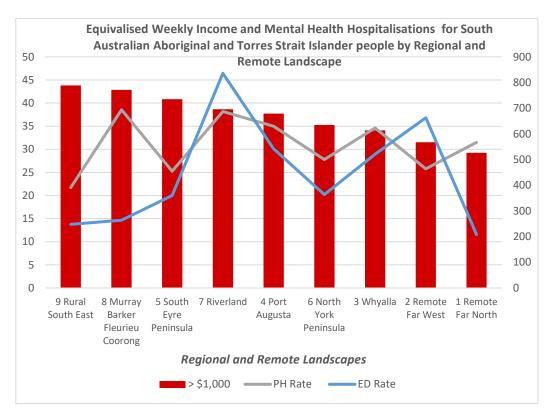
In the Aboriginal and Torres Strait Islander population, there were no distinct patterns between mental health hospitalisation rates and equivalised household income, in urban, regional and remote Landscapes. In urban areas Aboriginal and Torres Strait Islander households with the highest proportions of equivalised income >\$1,000 included; Inner South Metro (56.9%), City East Metro (52.7%), West Metro (50.5%) and Inner North Metro (49.3%). City East Metro households had the second highest equivalised weekly income >\$1,000 (52.7%) and the highest rate of hospitalisation for mental health (941 per 1,000 population).

Figure 3.10: Equivalised Weekly Income and Mental Health Hospitalisations,
Aboriginal and Torres Strait Islander people by urban Landscapes, South Australia,
2011-2018



In regional and remote Landscapes proportions of Aboriginal households which had equivalised weekly incomes >\$1,000 ranged from 44% to 29%. The Aboriginal and Torres Strait Islander populations in regional and remote Landscapes had comparable mental health hospitalisation rates between Rural South East with the highest proportion of equivalised weekly income (43.8%) and Remote Far West (31.5%) with the lowest.

Figure 3.11: Equivalised Weekly Income and Mental Health Hospitalisations,
Aboriginal and Torres Strait Islander people by regional and remote Landscapes, South
Australia, 2011-2018



#### Notes

- 1. PH Rate: Rate of Public Hospitalisations per 1,000 for the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing
- 2. ED Rate: Rate of Emergency Department presentations per 1,000 for the place of residence (Landscape) at time of presentation. Data Source: ISAAC, SA Department of Health and Ageing
- 3. Income: Households with a weekly Equivalised household income greater than \$1,000 by place of residence (Landscape) as at 2016 Census. Data Source: South Australian Aboriginal Landscape Reports. Census data sourced from Australian Bureau of Statistics, 2016 Census of Population and Housing, South Australia, Indigenous Profile, downloaded November 2017.

Includes occupied private dwellings only. Cells and continuous variables in the underlying data have been randomly adjusted by the ABS to avoid the release of confidential data. Discrepancies may occur between sums of the component items and totals.

# 3.4 Discussion

# 3.4.1 Mental health and the Social Determinants of Health

This study set out to explore the relationship between mental health outcomes and the social determinants of health in Aboriginal and Torres Strait Islander communities in South Australia. Despite an underlying strengths-based approach to this study, the story told by the data highlights pervasive unmet needs. Among the Aboriginal and Torres Strait Islander population there were high rates of hospitalisation and emergency department admissions for mental health. Across most social determinants of health and between Landscapes, similar patterns were observed with 50% or less of the Aboriginal and Torres Strait Islander population achieving year 12 attainment, in employment and with household incomes above the poverty line (equivalised weekly income >\$1000). Where communities in Landscapes had slightly above 50% of Aboriginal and Torres Strait Islander households with incomes above the poverty line, similar or consistent mental health rates were observed in those Landscapes (range 300-442 per 1,000 population). In comparison, Landscapes with higher proportions of Aboriginal and Torres Strait Islander households below the poverty line also had high mental health hospitalisations.

There were some observable geographic variations in remote areas Landscapes which appeared to have lower rates of mental health hospitalisations and emergency department presentations compared to regional and some urban Landscapes. For example, emergency department presentations for Remote Far North (200 per 1,000 population) were much lower compared to the Riverland (836 per 1,000 population) and Inner South Metro (775 per 1,000 population). Some explanations may include that these very remote areas have challenges to hospital and health care access, and this may not be representative of the mental health needs but more likely challenges of access to mental health care services (Meadows et al. 2015).

In urban Landscapes there was one Landscape which drew attention. City East Metro is well-known for being 'affluent', however this region had both high hospitalisations and emergency department presentations compared to all Landscapes. There may be many possible explanations; of note is the potential influence of housing insecurity and homelessness within the region. Adelaide City has the highest proportion of those experiencing homelessness in South Australia (Flavel et al. 2021). The results of this

study highlighted that City East Metro had a high proportion of "other dwellings" which is often less secure housing, and it may be possible that place of residence at hospitalisation could be for the homeless shelters or mental health facilities which are also located in the region. Unfortunately, the data do not include details on other housing variables.

The findings of this study highlight that while some Landscapes showed slightly lower or higher hospitalisations and/or emergency department presentations, the rates of mental health hospitalisations were consistent across the state. This finding is consistent with data from the Health Performance Framework which found that South Australian Aboriginal and Torres Strait Islander mental health hospitalisations were above the national average and well above the non-Indigenous population in South Australia and nationally (Australian Institute of Health and Welfare 2020e).

## 3.4.2 Mental Health Data Limitations

Critiques of hospitalisations as an outcome measure for mental health emphasise that there is more to mental health and wellbeing than hospital admissions, which is also consistent with Aboriginal and Torres Strait Islander philosophies of health and wellbeing (Burns 2007; Dudgeon, Milroy & Walker 2014). Mental health conditions cover a range of disorders with varying severity and hospitalisations for mental health and represent the more acute end of the mental health spectrum. Most mental health emergency department presentations in Australia include four principal diagnosis groupings 1) Mental and behavioural disorders due to psychoactive substance use (representing 26.7% of national mental health emergency department presentations); 2) Neurotic, stress-related and somatoform disorders (representing 26.9% of national mental health emergency department presentations); 3) Schizophrenia, schizotypal and delusional disorders (representing 11.6% of national mental health emergency department presentations; and 4) Mood (affective) disorders (representing 9.3% of national mental health emergency department presentations) (Australian Institute of Health Welfare 2022). These national proportions are not specific to Aboriginal and Torres Strait Islander populations however they highlight more broadly that hospitalisations tend to represent psychotic episodes (Australian Institute of Health Welfare 2022).

Outside of hospitalisations, available data indicates that in 2018-19 an estimated 24% of Aboriginal and Torres Strait Islander people self-reported a mental health or behavioural condition (Australian Institute of Health and Welfare 2022) with anxiety (17%) and depression (13%) the most commonly reported. Surveys conducted throughout April 2010–March 2015 found that 11% of all needs managed by general practitioners among Indigenous patients were related to mental health, these included depression (47 per 1,000 encounters) and anxiety (23 per 1,000 encounters) (Australian Institute of Health and Welfare 2020e). In 2016-2017, Indigenous primary health care services reported on the staffing and organisational resources which were provided for social and emotional wellbeing services. Social and emotional wellbeing services were provided primarily for depression, anxiety and stress, grief and loss issues, family and community violence and family and relationship issues (Australian Institute of Health and Welfare 2020e). There is a high likelihood that significant events or experiences would result in a mental health hospitalisation or that care was otherwise unavailable. Furthermore, anxiety or depressive disorders are more likely to be addressed outside the acute or tertiary setting.

In South Australia, mental health services are provided in specialised mental health hospitals and facilities, within designated wards in general hospitals, and also in the community through visits and outpatient services with data captured in all of these settings (South Australian Mental Health Commission 2017). Evidence has highlighted that hospital administrative data is not particularly accurate for disorders which are more 'ambiguous' e.g., anxiety disorders (Berkman 2000; Davis, Sudlow & Hotopf 2016). Many people access mental health support through community mental health services. While community mental health data are available, challenges of understanding the burden of mental health exist due to reporting "separations/episodes of care" which can be the same person, returning for a group program, an individual session or both, over a period of time. Therefore, community mental health data were not utilised in this study. The advantages of using hospitalisation as an outcome measure is that it is generally understood what someone needs if they are admitted to hospital with a mental health condition (Burns 2007). There are no specific collections or measures for Aboriginal and Torres Strait Islander mental health and in the absence of comprehensive and culturally relevant mental health outcome data, administrative hospitalisation data provides the most accessible source for mental health outcomes at the population level.

There are also limitations regarding the accuracy of hospital data for mental health, including cultural limitations of existing diagnostic tools and clinical assessments combined with potential under-identification of Indigenous status in the hospital system, stigma, and accessibility (Burns 2007; Davis, Sudlow & Hotopf 2016; Haswell-Elkins et al. 2007; Mahoney 2017). All of these factors can contribute to the under-identification of mental health conditions for Aboriginal and Torres Strait Islander people and therefore the true hospital burden/impact of mental health for the communities in this study may potentially be much higher than reported. Mental health hospitalisations provide important insights into the acute mental health outcomes experienced by Aboriginal and Torres Strait Islander people. However, outcome measures are needed which adequately reflect the burden, experience and impact of mental health on Aboriginal and Torres Strait Islander communities in order to respond and monitor the quality of those responses (Haswell-Elkins et al. 2007). Additionally, these measures need to be driven by communities and have a focus on the concept of social and emotional wellbeing and wellness to align with Aboriginal and Torres Strait Islander knowledges.

# 3.4.3 The Social Determinants of Health

This study highlighted key stories for the social determinants of health which will be summarised in the following sections.

#### Education

The results in this study found less than 50% of the population in most Landscapes reported Year 12 attainment or equivalent. The 2008 NATSISS survey found that those who had completed Year 12 were less likely to have reported high/very high levels of psychological distress in the last four weeks (ABS 2010). The National Closing the Gap Prime Ministers Report (2018) outlined that attainment targets were trending upwards with the proportion of Indigenous 20–24 year olds who had achieved Year 12 or equivalent increasing from 47.4% in 2006 to 65.3% in 2016 (Commonwealth of Australia 2018a). South Australia had one of the greatest increases over the previous decade with year 12 attainment rates rising by more than 20 percentage points (Commonwealth of Australia 2018a). Despite these considerable increases in Year 12 attainment for younger

age cohorts over the last ten years, the total Aboriginal and Torres Strait Islander population in South Australia continue to have low education attainment.

Evidence on mental health and education has found that higher education levels are associated with lower risk of major mental disorders and may be a protective factor for depressive symptoms and psychological distress (Assari 2018; Yuan et al. 2021). Research which has explored education and Indigenous health outcomes highlights the potential for education to support increased empowerment and autonomy which have been shown to contribute to increased self-reported wellbeing (Biddle 2006). Evidence indicates that a low level of educational attainment increases risk of unemployment, limits likelihood of obtaining a job that pays a living wage, and is associated with lower levels of health literacy (Markwick et al. 2014). Further, life expectancy may be increased by up to 12 years by improving educational attainment in the general population (Baker et al. 2011; Hart, Moore & Laverty 2017) and as such there are strong arguments that a focus on education attendance, achievement and attainment should be implemented as a priority (Hart, Moore & Laverty 2017; Johnston, Lea & Carapetis 2009).

There are a range of targets outlined for Aboriginal and Torres Strait Islander education as part of Closing the Gap including school attendance, literacy and numeracy and year 12 attainment (Productivity Commission 2021). However, it remains unclear how health and education sectors work towards achieving these targets as part of holistic approaches that promote social and emotional wellbeing. Further research is needed to explore educational attainment and its relationship with health outcomes, as well as how health and education sectors can work together to address holistic health needs.

## Employment and Income

Results of this study highlight that consistently between Landscapes, the proportion of the population engaged in employment was often less than 50% and high proportions of people across all Landscapes were not participating in the labour force. Income results from this study highlighted that across Landscapes there were significantly high proportions (more than half in most instances) of households which had an income of less than \$999. Nationally at the 2016 Census, the mean gross weekly equivalised household income for Aboriginal and Torres Strait Islander households was \$802 (Australian Institute of Health and Welfare 2020d). The employment and income results of this study

are consistent with national trends reported in the Health Performance Framework (Australian Institute of Health and Welfare 2020c). In 2018-19, of working-age people (15-64 years), 49% were employed which remains unchanged from 2008 (Australian Institute of Health and Welfare 2020c). Of those Aboriginal and Torres Strait Islander people who were unemployed, 42% reported high or very high levels of psychological distress (Australian Institute of Health and Welfare 2020c).

Income is made up of wages from employment or government allowances for job seekers, unemployed, students and parents. The national minimum wage is \$812.60 per week and the Australian Council of Social Services (ACOSS) estimates that the national minimum wage and government allowance amounts are well below what is required to maintain basic essentials such as food, transport and healthcare (ACOSS 2019). In 2018-2019, 45% of Aboriginal and Torres Strait Islander people 18-64 years old received a government allowance as their main source of income (Australian Institute of Health and Welfare 2020d). Further, for the same period 40% of Aboriginal and Torres Strait Islander adults were living in households that had experienced days without money for basic living expenses, such as for food, clothing and bills (Australian Institute of Health and Welfare 2020d).

There is an established relationship between unemployment and an increased risk of mental health problems (Milner et al. 2014; Nam et al. 2021). Nam et al. (2021) found that for young adults, unemployment status was significantly associated with an increased risk of mental health symptoms including depressive moods and suicide ideation. For Aboriginal and Torres Strait Islander populations, mental health and wellbeing is associated with a greater likelihood of participating the workforce (Kalb et al. 2012). Contrary to this, there is also some evidence that employment can place Aboriginal and Torres Strait Islander people at greater risk of experiencing racism which has been linked with poor mental health (Cunningham & Paradies 2013; Nicholas et al. 2013; Paradies & Cunningham 2012). Access to employment is linked with income and financial security and is considered to provide a greater sense of wellbeing and autonomy for people (Crowe, Butterworth & Leach 2016). Additionally employment and income provides opportunities to access health care and may also be associated with health literacy and prevention (Markwick et al. 2014).

Aboriginal and Torres Strait Islander communities are collective, resources are shared and there are a range of family and kinship cultural considerations for employment and labour force participation. Aboriginal and Torres Strait Islander people often take on caring responsibilities, which can impact on ability to participate in the labour force (Belachew & Kumar 2014; Kalb et al. 2012; McRae-Williams & Gerritsen 2010; Topp, Edelman & Taylor 2018; Walter 2016). In 2016, 31.7% of Aboriginal and Torres Strait Islander people provided care for children and 13.7% assisted family members or others due to a disability, long term illness or old age in the two weeks before the Census (Australian Bureau of Statistics 2016a). Aboriginal and Torres Strait Islander kinship obligations require family and community to support each other in multiple ways including financially and evidence has shown that large family units and large household bills impact choices and access to resources, such as food (McCarthy, Chang & Brimblecombe 2018).

Nationally agreed priorities of the closing the gap reform currently include two targets which directly relate to employment. One is to increase the proportion of Aboriginal and Torres Strait Islander youth (15–24 years) who are in employment, education or training from 57% to 67% by 2031 Aboriginal and Torres Strait Islander. The second is to increase Aboriginal and Torres Strait Islander people aged 25–64 years who are employed from 51% to 62% by 2031 (Australian Institute of Health and Welfare 2022a). There are currently no targets relating to income or to addressing the inadequacy of the national minimum wage or government pensions and allowances, leaving a considerable systemic gap. Future research needs to consider informing collection of measures around employment and income to ensure impacts on health and wellbeing can be explored. Additionally, health system and service provision approaches require evidence to inform responses which address these needs as part of responses to promote social and emotional wellbeing.

# Housing

Study findings for housing included a mixture of Landscapes with high proportions (80%) of households with 'secure' (either owned or renting) housing along with Landscapes where only 40% of households were in secure housing. Interestingly, this pattern was similar for both urban and regional/remote Landscapes. In 2018-19, national survey data

found 34% of Aboriginal and Torres Strait Islander adults lived in houses rented through social housing and 33% rented privately, through a real estate agent or other arrangement (Australian Institute of Health and Welfare 2020b). There were variations in tenure type depending on remoteness status. In urban and regional areas, the same proportion of households were renting through real estate agents (36%) and were homeowners (36%). In remote areas 71% of households rented from a social housing provider (Australian Institute of Health and Welfare 2020b).

Refreshed national closing the gap priorities now include an outcome aimed at having Aboriginal and Torres Strait Islander peoples in secure appropriate, affordable housing that is aligned with their priorities and needs (Productivity Commission 2021). Additionally, there is a target to increase the proportion of Aboriginal and Torres Strait Islander people living in appropriately sized (not overcrowded) housing from 82% to 88% by 2031 (Australian Institute of Health and Welfare 2020b). Evidence indicates there is a significant association between poor-quality housing and poor physical and mental health (Baker et al. 2016). There is an established relationship between tenure type and exposure to housing problems (Andersen et al. 2017). For example, social housing tenants were more likely to report physical dwelling problems than those in owned or privately rented homes but least likely to report affordability problems (Andersen et al. 2017). There have been varied policy responses to housing for Aboriginal and Torres Strait Islander populations, in urban areas there has been a shift away from public housing as part of privatisation where public housing stock has been sold off or demolished to make way for private land sales (South Australian Council of Social Services 2021). In remote areas there are ongoing housing complexities such as overcrowding and poor living conditions (Andersen et al. 2017; Johnston et al. 2013; Lowell et al. 2018).

In the Health Performance Framework housing is articulated as an environmental determinant, however there are aspects of housing which cross-over between both environmental and social determinants of health (Mansour et al. 2022). Housing has a significant social aspect relating to access, affordability and security including factors such as homelessness and insecure tenure (Mansour et al. 2022). Environmental housing relates to suitability and includes factors such as the physical condition, appropriateness, and suitability for purpose of the housing environment once it is secured (Mansour et al. 2022). Throughout this thesis, housing is conceptualised and implemented to reflect the social aspect of housing. For housing, complex understandings of quality, security and

affordability of those dwellings are not captured or easily available as data constructs (Biddle 2017). As highlighted by the findings of Andersen et al (2017), tenure type matters and while more culturally relevant data in relation to homelessness and overcrowding is available, this is not collected through Census data and is only available by Primary Health Network. Data available in this study did not explore other measures of healthy housing such as suitability, affordability and over-crowding (Biddle 2017; Mansour et al. 2022). Healthy housing is an important consideration of overall wellbeing. Further understandings are needed of housing suitability and affordability. For affordability, housing solutions must also consider the impact of declines in the availability of social housing and associated financial implications for Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare 2020b).

#### 3.4.4 Cultural Determinants Considerations

Indigenous social determinants of health include the unique cultural, historical and political factors presented in Chapter One (Anderson, Baum & Bentley 2004; Morrissey 2003). The Health Performance Framework combines cultural determinants as 'community capacity'. From an Indigenous knowledge perspective, these factors are key domains of social and emotional wellbeing (Dudgeon, Milroy & Walker 2014). Considering Aboriginal and Torres Strait Islander understandings of social and emotional wellbeing domains and cultural determinants of health (Gee et al. 2014), factors used to measure community capacity, with the exclusion of contact with criminal justice system, would be considered cultural determinants of health (Lowitja Institute 2014). Community safety is a metric for *community connection*, while child protection is an underlying measure of *family and kinship*. These are examples of how measures are often framed to reflect the 'problem' or 'risk', which is how these constructs and concepts are currently measured (Walter 2018). To recognise the overarching constructs of these measures as important aspects of social and emotional wellbeing, these factors have been included where possible and relevant throughout this thesis. Further, an intentional shift has been made away from deficit discourses for these constructs within this thesis to reflect and align with strengths-based approaches and social and emotional wellbeing definitions.

Data for cultural determinants of health are continuously emerging and there are some existing surveys which have included specific cultural questions. The ABS implement

specific surveys for targeted populations, the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) and the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) were introduced in 1994, with the intent to more accurately capture the health status, lived experiences and other culturally relevant information about Aboriginal and Torres Strait Islander populations (Biddle 2014a). Whilst these national surveys provide a range of important information, they have limitations in their use for exploring community level data. Data are only available for a large geographic unit as defined by the Primary Health Network boundaries and not smaller geographic units that are available for Census data (SA2). There are a total of 31 PHN regions in Australia. There are 2,473 SA2s covering the whole of Australia, the purpose of SA2s is to represent a community that interacts together socially and economically (Australian Bureau of Statistics Jul2021-Jun2026,). Lastly, these surveys are implemented for a sample of the population (approx. 33% of the Aboriginal and Torres Strait Islander population) and are not mandatory and may result in undercoverage (Australian Bureau of Statistics 2018-19). Whilst NATSISS and NATSIHS comprise expressions of Cultural Connection and Transport domains, which align with the conceptualisation of the social determinant of health domains in the Health Performance Framework (Australian Health Ministers' Advisory Council (AHMAC) 2017), these were not included because their expression is limited to Primary Health Network and not possible by Landscape or available at the same spatial units as Census data.

# 3.4.5 Indigenous methodology and empowering Landscapes

The underpinning Indigenous methodology of the PhD program of work supports a strengths-based quantitative approach to understanding Aboriginal and Torres Strait Islander health and social needs and ensures alignment of statistical methods with Indigenous ways of knowing, being and doing. Quantitative research, including epidemiology, has contributed to and perpetuated negative discourses, problematised communities and been used to implement harmful, oppressive and damaging policies and practices (Askew et al. 2020; Walter 2016; Walter & Andersen 2013). In quantitative research, Indigenous methodology informs the who, how and what in which statistical tools/methods are used (Walter & Andersen 2013). As part of the Indigenous methodology this study does not compare Indigenous populations to non-Indigenous

populations. Further, the selection and expression of variables has a focus on the strengths of communities (Walter 2018) and the associations between mental health outcomes and key measures of the social determinants of health. As part of the underpinning Indigenous methodology, a knowledge translation plan will be developed in partnership with the SA Aboriginal Landscape Project to empower communities to utilise this data accordingly to suit their needs.

#### 3.4.6 Future Research

This study highlights a range of future research needs and topics to expand knowledges on drivers of mental health and social and emotional wellbeing outcomes. Specifically, this study utilised an ecological approach to contribute to fundamental understandings and provide insights into approaches to target interventions (Berkman 2000; Bonita 2006). As Berkman (2000) outline, ecological studies contribute to foundational understandings on topics such as relationships between socio-economic variables representing constructs of the social determinants of health and health outcomes across communities. Associations at the group level cannot be used to infer the same would apply at the individual level, however, they can still be a useful starting point for more detailed epidemiological studies (Berkman 2000; Bonita 2006). Future research on mental health and the social determinants of health should include individual explorations of the relationship between social and cultural determinant of health variables and mental health and wellbeing. These explorations should be used to inform and empower communities and contribute to action aimed at addressing unmet needs. Additionally, these understandings need to utilise data sources which are culturally relevant and align with community priorities. Community ownership over data which includes informing and designing data collection items across health systems becomes increasingly necessary to inform solutions which are self-determined by Aboriginal and Torres Strait Islander communities.

# 3.5 Conclusion

Whilst this study was descriptive in nature to detail place-based understandings on mental health outcomes and key measures that represent the social determinants of health, it highlights that across all local geographic regions (Landscapes) there are evident high mental health hospitalisation rates, potentially indicating that existing care is not meeting the communities needs for mental health care and treatment (Davis, Sudlow & Hotopf 2016; Dudgeon et al. 2021). The social determinants are impacting all local geographic regions, with many communities experiencing high proportions of social factors that are below average, contributing to significant unmet social needs and challenges to improving health and wellbeing outcomes. This evidence further contributes to the critical need for action to addressing the social determinants of health. Importantly, there still remains a gap between what is known about the social determinants associated with health outcomes and evidence of effective action to improve health and wellbeing within and across populations (Bambra et al. 2010; Smith et al. 2018). There has been a consistent argument from Aboriginal and Torres Strait Islander health care providers and academics for holistic wellbeing responses, which supports embedding social and cultural determinants of health.

Furthermore, this study highlights the need for enhanced understandings, access to and utilisation of culturally relevant data to inform mental health care service delivery and planning for Aboriginal and Torres Strait Islander communities. The use of administrative data for understandings of mental health presents a range of challenges relating to accuracy and cultural relevance. Hospitalisations provide insight into 'acute' mental health conditions, however, the true 'burden' of mental health is likely to be much higher than represented by hospital data. There are limitations of ecological studies which are not able to draw conclusions or correlations between mental health outcomes and the social determinants of health. However, the combined descriptions of the two highlight there are significant burdens of education, employment, housing, income and mental health experienced by all South Australian Aboriginal and Torres Strait Islander communities.

# **CHAPTER FOUR:**

# IDENTIFYING HEALTH PROGRAMS THAT ADDRESS SOCIAL DETERMINANTS OF HEALTH

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#### **PRELUDE**

As Chapter Three outlined, there is a need for stronger data collections and measures at the individual level to understand the impact of the social determinants of health on a range of health outcomes for Aboriginal and Torres Strait Islander people. There are few examples of evidenced-based approaches on how to take action in practice, influencing the ways in which determinants of health contribute to and shape such outcomes. Further to this, such limitations in our understandings extend to the evidence base of health care programs addressing the social determinants of health for Aboriginal and Torres Strait Islander people. In 2013, a review was undertaken to identify actions that address social and economic determinants of Indigenous Health (Osborne, Baum & Brown 2013). The review found many actions focused on specific social domains, for example, education, and housing. However, these were not directly aimed to improve health outcomes specifically and were more likely to target their respective domain, for example, education programs focussed on education outcomes such as school attendance (Osborne, Baum & Brown 2013). There remains pressing need for evidence-based understandings of what works to address the social determinants of health in practice including cultural and contextual understandings as well as the approaches taken in practice (Brownson, Fielding & Maylahn 2009; Dudgeon et al. 2014; Kelaher et al. 2018; Osborne, Baum & Brown 2013; Zubrick et al. 2014)

A scoping review supports accessing a breadth of information and evidence to develop foundational understandings on specific topics. A scoping review whilst systematic in its steps is flexible. To be consistent with an Indigenous methodology the scoping review method required enhancement. Indigenous knowledges were integrated into the scoping review method through the Advisory Group. The Advisory Group, through a partnership approach, were involved in the development of the review question, criteria, search strategy, interpretation of findings and plans for dissemination and knowledge translation. This scoping review is part of an iterative study design to identify current evidence from programs which address the social determinants of health with findings utilised to inform Cultural Pathways Program development (Chapter Five) including the approaches, processes and measures/data collection.

This Chapter is formatted as two separate manuscripts: the first paper outlines the enhancement of the scoping review method and; the second details the results.

# 4.1 ENHANCEMENT OF SCOPING REVIEW METHODOLOGY TO REFLECT ABORIGINAL AND TORRES STRAIT ISLANDER WAYS OF KNOWING, BEING AND DOING

This section is formatted as a peer-reviewed manuscript submitted for publication:

Brodie T, Pearson O, Canuto K, Brown A, Howard NJ. (Under Review). Enhancement of scoping review methodology to reflect Aboriginal and Torres Strait Islander ways of knowing, being and doing. *Australian New Zealand Journal of Public Health*, Submitted for publication 5 October 2022.

# Statement of Authorship

| Title of Paper      | Enhancement of scoping review methodology to reflect Aboriginal and Torres Strait Islander ways of knowing, being and doing.   |
|---------------------|--|
| Publication Status  | <ul> <li>Published</li> <li>Accepted for Publication</li> <li>✓ Submitted for Publication</li> <li>Unpublished and Unsubmitted work written in manuscript style</li> </ul> |
| Publication Details | Submitted to the Australian New Zealand Journal of Public Health (ANZJPH) in October 2022, has been reviewed and recommended for publishing in February 2023.              |

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| Name of Principal Author (Candidate) | Tina Brodie  |      |               |  |  |  |  |
|--------------------------------------|--|------|---------------|--|--|--|--|
| Contribution to the Paper            | TB implemented the enhanced method and prepared this manuscript.  The Advisory Group chaired by the candidate were integral in the implementation of the method expansion and provided reviewed this manuscript.   |      |               |  |  |  |  |
| Overall percentage (%)               | 60   |      |               |  |  |  |  |
| Certification:                       | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper. |      |               |  |  |  |  |
| Signature                            |  | Date | 11 April 2023 |  |  |  |  |

#### **Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate in include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

| Name of Co-Author         | Natasha Howard  |      |               |  |  |  |  |
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| Contribution to the Paper | NH provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the enhancement and the writing of this manuscript. |      |               |  |  |  |  |
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| Name of Co-Author         | Odette Pearson   |      |               |  |  |  |  |
|---------------------------|--|------|---------------|--|--|--|--|
| Contribution to the Paper | OP provided leadership advice and guidesign, the implementation of the enhance |      |               |  |  |  |  |
| Signature                 |  | Date | 13 April 2023 |  |  |  |  |

| Name of Co-Author         | Kootsy Canuto   |  |  |  |  |  |  |
|---------------------------|---|--|--|--|--|--|--|
| Contribution to the Paper | KC provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the enhancement and the writing of this manuscript. |  |  |  |  |  |  |
| Signature                 | Date 11 April 2023  |  |  |  |  |  |  |

| Name of Co-Author         | Alex Brown  |      |               |  |  |  |  |
|---------------------------|---|------|---------------|--|--|--|--|
| Contribution to the Paper | AB provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the enhancement and the writing of this manuscript. |      |               |  |  |  |  |
| Signature                 |   | Date | 12 April 2023 |  |  |  |  |

#### 4.1.1 Abstract

#### **Objective**

This paper argues for the enhancement of the scoping review method to incorporate Indigenous ways of knowing, being and doing for more effective understandings of evidence of importance to Indigenous populations.

#### Methods

Scoping review methodology typically aims to understand existing evidence and support translation of evidence into practice. Levac and colleagues' (2010) scoping review methodology six stages: 1) Identify the research question; 2) Identify relevant studies; 3) Study selection; 4) Charting the data; 5) Collating, summarizing and reporting results; and 6) Consultation were considered from the perspective of Indigenous knowledges and adapted accordingly.

#### Results

The scoping review method can be enhanced to better align with Indigenous methodologies which are based on relationality, collaboration, partnership, reciprocity, and benefit. Consultation was redefined in this enhancement as *partnership* and integrated throughout the scoping review stages, which are underpinned by key methodological principles.

#### Conclusions

An enhancement of the scoping review stages with Indigenous ways of knowing, being and doing has the potential to strengthen the utility of the scoping review method to better meet the needs of and ensure relevance for Indigenous populations.

# Implications for public health

These enhancements can increase the potential for knowledge translation and implementation of culturally relevant evidence-based approaches into practice for Indigenous populations and for other populations who experience health inequities.

*Keywords:* Indigenous Knowledge; Aboriginal and Torres Strait Islander Knowledge; Methodological Framework; Scoping review; Knowledge Translation; Culturally Responsive; Indigenous Engagement; Participatory.

# 4.1.3 Objective

Research with Indigenous<sup>6</sup> communities and by Indigenous researchers has continued to evolve over time (Wilson 2008). The majority of research with Indigenous populations, prior to the 1990s, had been characterised by dominant discourses and legacies of ethnocentrism which problematised communities and positioned Western science as having the only solutions to "Indigenous problems". These discourses have failed to recognise the contextual influences of racism, discrimination, dispossession and oppression in the creation of these 'problems' (Kendall et al. 2011; Moreton-Robinson 2004, 2013; Moreton-Robinson & Walter 2009; Walter & Andersen 2013). The emergence of Indigenous and decolonising methodologies by Indigenous academics throughout the 1990s, which prioritised Indigenous wisdom and knowledges, coincided with a shift towards the implementation of ethical research frameworks (Kendall et al. 2011; Smith 2012; Wilson 2008). Additionally, the emergence of social sciences, feminism and participatory approaches offered alternative points of view and challenged prevailing and dominant discourses of non-Indigenous research (Cargo & Mercer 2008; Kendall et al. 2011; Wilson 2008). In an Australian context, the emergence of accountability and ethical structures have been embedded in health research to ensure quality and safety of research with Indigenous communities. These structures contribute to research projects which are relevant, effective and respectful (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; Dudgeon, Kelly & Walker 2010; Jamieson et al. 2012; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014).

The emergence of Indigenous methodologies was an active reclamation of space, of colonial resistance and self-determination (Smith 2012). Indigenous scholars in Australia and New Zealand created opportunities for the prioritisation of Indigenous methodologies and methods that are both culturally relevant and responsive to the needs of Indigenous communities (Martin-Mirraboopa 2003; Rigney 1999; Smith 2012). An Indigenous methodology is underpinned by ontology (ways of being / how we perceive our reality), epistemology (ways of knowing / how we think about it), and axiology (ways of doing /

<sup>&</sup>lt;sup>6</sup>The term Indigenous is used to refer globally to Indigenous or First Nations populations including Aboriginal and Torres Strait Islander populations. Aboriginal and Torres Strait Islander is used when referring specifically to this context and population.

values and beliefs). An Indigenous methodology from an Aboriginal and Torres Strait Islander perspective requires that research responds to community driven priorities, is of benefit to the community and is grounded in relationality, partnerships, and reciprocity (Martin-Mirraboopa 2003; Moreton-Robinson & Walter 2009; Rigney 1999; Smith 2012; Wilson 2008). An Indigenous methodology can include both Indigenous and non-Indigenous methods, however, it is always consistent with Indigenous ways of knowing, being and doing. Indigenous methodologies centre Indigenous knowledge and understanding and then identify the most appropriate method to meet that need (Wilson 2008). Those methods are then adapted as necessary through the process of decolonising. Decolonising is an approach which involves unravelling and challenging dominant or Eurocentric discourses across systems and structures (Smith 2012). An example in a research context of decolonising methods is to challenge dominant methods which can contribute to or perpetuate oppression and disempower communities (Smith 2012). Decolonising methods on their own are applied within predominantly Western frameworks to adapt methodologies and methods to incorporate or better suit Indigenous ways of knowing, being and doing (Smith 2012).

Reviewing literature and evidence can be a culturally relevant way to communicate with "dominant system academia" (Wilson 2008). The process of reviewing evidence acknowledges and builds upon cultural knowledge and stories by sharing what is already known from an evidence-based perspective (Wilson 2008). For Indigenous contexts and populations, culturally relevant understandings can enhance implementation and uptake of research and more effectively translate into improved health and wellbeing outcomes (Cochran et al. 2008; Harfield, Pearson, et al. 2020; Smith 2012). The process of integrating cultural ways of knowing, being and doing, particularly story-telling and sharing, with processes for systematically reviewing evidence is not common in health research.

From an Indigenous knowledge perspective, the process of sharing or storytelling is consistent with cultural practices (Wilson 2008). Within non-Indigenous research, reviews of evidence are conducted across diverse contexts for different reasons, questions of interest and evidence types. The two most common review types include systematic

reviews and scoping reviews, which have seen considerable growth in use (Peters et al. 2015). The process of systematically reviewing primary research enables the documentation of understandings of what has been tried, effectiveness, gaps in evidence, and informs evidence-based practice in health services and systems (Peters et al. 2015). A scoping review method (Arksey & O'Malley 2005) is well suited for topics which require access to a breadth of peer reviewed and grey literature and therefore is particularly useful for understandings and research questions of importance to Aboriginal and Torres Strait Islander people (Clive 2009). The scoping review method outlined in published review guidelines outlines six stages: 1) Identify the research question; 2) Identify relevant studies; 3) Study selection; 4) Charting Data; 5) Collating, reporting and summarising the results; and 6) Consultation (Levac, Colquhoun & O'Brien 2010). Scoping review methods have continued to be enhanced to enable consistent and standardised approaches, although, there are still inconsistencies in applying these guidelines (Colquhoun et al. 2014; Levac, Colquhoun & O'Brien 2010; Peters et al. 2015; Tricco et al. 2016). For example, an evaluation of the methodology in 2014 highlighted the need for clarity for inclusion criteria and presentation of results (Khalil et al. 2020). Further, inconsistency in the conduct of reviews resulted in clearer guidance developed by JBI (Joanna Briggs Institute) with an aim to improve the utility of the method (Peters et al. 2015).

Participatory, collaborative and consumer driven research continues to gain momentum internationally with health services increasingly implementing consumer engagement strategies and researchers considering how they can involve consumers and stakeholders in the research process (Cargo & Mercer 2008; Miller et al. 2017). Despite this focus, published scoping reviews rarely describe the processes undertaken within the consultation stage, or undertake this stage at all (Pollock et al. 2022; Tricco et al. 2016). This paper argues that through prioritising Indigenous ways of knowing, being and doing this process can not only contribute to, but enhance, scoping review methods.

#### 4.1.4 Methods

The described methodological enhancement (Table 4.1) was developed and implemented by Wardliparingga Aboriginal Health Equity Theme of the South Australian Health and Medical Research Institute, Adelaide, South Australia. Consistent with an Indigenous methodology, the authors are part of and work with Indigenous communities (Redvers & Blondin 2020) and adhere to the ways of working defined by the South Australian Aboriginal and Torres Strait Islander community. The South Australian Aboriginal Health Research Accord (South Australian Health and Medical Research Institute 2014) requires that research is informed by community priorities, designed in partnership and benefits Aboriginal and Torres Strait Islander peoples and communities. Indigenous methodology principles of reciprocity, partnership, co-design and collaboration can be embedded into existing scoping review methods which currently include consultation and engagement (Moreton-Robinson 2013; Wilson 2008). The expanded method detailed in this manuscript allows for a collaborative approach that prioritises Indigenous knowledge, expertise and engagement.

The first enhancement of the scoping review methodology was to reconceptualise the stage of consultation to partnership which is grounded in relationality and integrated throughout the review stages. For the method described in this paper, the inclusion of Indigenous knowledges and expertise was embedded through an Advisory Group. The group was established with membership specifically selected for the research question. Membership includes both Indigenous community and relevant industry stakeholder knowledge and expertise. The Advisory Group is governed by Terms of Reference and the goal of the group is to provide advice and guidance on implementation, interpretation of findings and to inform recommendations which influence health systems, policy and practice. This manuscript outlines the process, benefits, challenges, and opportunities for expanding the scoping review method to integrate Indigenous knowledges. The following sections detail the Indigenous informed methodological enhancements for a partnership approach to the scoping review stages.

Table 4.1: Scoping Review Methodology – Integrating Indigenous Knowledge

| Stage  | Arksey and<br>O'Malley<br>(Arksey &<br>O'Malley 2005)  | Challenges (Levac,<br>Colquhoun & O'Brien<br>2010)  | Recommendations (Levac,<br>Colquhoun & O'Brien 2010)   | Integrating Indigenous<br>Knowledge   |
|--|--|---|--|---|
| 1)<br>Partnership  | Consumer and stakeholder involvement to suggest additional references and insights.  | This stage is originally listed as optional, and it is not clear about when, how and why to undertake consultation. | Should be an essential component with a clearly established purpose. Preliminary findings can be used as a foundation for consultation with incorporated opportunities for knowledge transfer and exchange.                      | A genuine partnership<br>approach based on<br>relationships and<br>collaborative processes<br>integrated across each<br>stage, moving beyond<br>consultation.   |
| 2) Identifying<br>the research<br>question                   | Clearly defined question provides breadth of coverage to inform subsequent stages.   | Scoping review questions are broad and establishing a purpose is not associated with a framework stage.             | Clear purpose, rationale and intended outcome with defined concept, population and outcomes of interest.   | Co-production of review question with a culturally relevant context, target population, and concept/outcome of interest.  |
| 3) Identifying<br>relevant<br>studies                        | Development of<br>search strategy<br>including search<br>terms, time<br>spans, sources<br>as well as<br>resources<br>available and<br>limitations. | Balancing breadth and comprehensiveness of the scoping review with feasibility of resources.                        | Research question and purpose guide the search strategy.   | <ul> <li>Flexible consultations<br/>and collaboration with<br/>cultural and industry<br/>expertise to identify<br/>additional studies.</li> <li>Breadth for topics with<br/>emerging peer<br/>reviewed evidence.</li> </ul> |
| 4) Study<br>selection  | Post hoc inclusion and exclusion based on criteria informed by the research question.  | Misleading – not a linear process and the process for decision making not defined.                                  | Iterative with reviewers meeting at the beginning, mid-point and final stages searching the literature, refining the search strategy, and reviewing articles for inclusion.  | <ul> <li>Co-produced selection criteria.</li> <li>Reviewers with cultural and content knowledge.</li> <li>Culturally grounded study selection.</li> </ul>   |
| 5) Charting<br>the data                                      | A data-charting<br>form is developed<br>and used to<br>extract data from<br>each study.  | The nature and extent of data to extract from included studies requires clarity.                                    | Data charting is collectively developed by the research team with an iterative process to charting updating through the extraction.  | <ul> <li>Co-developed<br/>extraction tool.</li> <li>Cultural Appraisal.</li> <li>Culturally relevant and<br/>useful data extracted<br/>for service<br/>provision/policy makers<br/>etc.</li> </ul>                          |
| 6) Collating,<br>summarising<br>and reporting<br>the results | Intended to present an overview of all material reviewed and requires a consistent approach to reporting all findings.                             | Limited detail and the<br>steps are summarised<br>as one framework<br>stage.  | Three distinct steps 1) Analysis including descriptive numerical summary and qualitative thematic 2) Reporting the results as per the intended purpose and 3) Implications of findings for future research, practice and policy. | Collaborative synthesis of findings to ensure accuracy, representative of experiences and have practical utilisation e.g knowledge translation and benefit to community.  |

Adapted from Levac, Colquhoun and Obrien 2010 "Scoping Studies: advancing the methodology".

## 4.1.5 Results and Discussion (The enhancements)

#### 1. Partnership

Participatory approaches are increasingly used in Indigenous research because of their ability to recognise that people are influenced by the contexts in which they live (Baum, MacDougall & Smith 2006; Cargo & Mercer 2008; Cornwall & Jewkes 1995). Participatory research is underpinned by partnership approaches which involve researchers and stakeholders collaboratively working together in the implementation and translation of research (Cargo & Mercer 2008; Khalil et al. 2020). Partnership approaches to research with Aboriginal and Torres Strait communities should be grounded in the establishment of mutual trust that enables Aboriginal and Torres Strait Islander people to have an integral role in research which effects their lives and communities (South Australian Health and Medical Research Institute 2014). Partnership approaches described in this enhancement are based on relationships and collaborative processes which move beyond consultation. Approaches which keep the end-user in mind when planning and implementing research, require that research priorities and questions align with community needs (Miller et al. 2017). Priorities for research should arise from and have the endorsement of the community (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014).

The involvement of community and key stakeholders in developing research proposals and plans enhances acceptability, relevance and accountability (Miller et al. 2017). Governance structures such as Reference Groups or Advisory Groups are often established to ensure that research addresses community priorities and enables the community to inform the methods and provide guidance throughout the research process (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; Hunt 2013; Laycock 2011; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014).

Approaches to governance, including membership, meetings and frequency can be flexible depending on the research project and question. Partnership approaches should be genuinely considered and integrated throughout the research process (Bond, Foley & Askew 2016; South Australian Health and Medical Research Institute 2014). Such approaches enable the integration of knowledges for enhanced meaning, understanding

and interpretation of research findings strengthening their relevance and ability to meet community identified priorities.

#### 2. Identify the Scoping Review research question

The starting point for a scoping review requires careful consideration to identify the question which will subsequently shape a clear purpose or aim, the search strategy and inclusion criteria (Arksey & O'Malley 2005; Levac, Colquhoun & O'Brien 2010). Detailed processes to identify the review question will allow for parameters and implications of specifying particular population groups, interventions or outcomes to be fully considered (Arksey & O'Malley 2005). For a scoping review it is recommended that review questions are broad with a clearly articulated scope of inquiry (Arksey & O'Malley 2005; Levac, Colquhoun & O'Brien 2010). The recommended approach for scoping reviews includes defining the population, concept and context. A partnership approach can be achieved from the inception of the review by being guided by ethical research and accountability processes defined by Indigenous peoples (Dudgeon, Kelly & Walker 2010; Jamieson et al. 2012; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014). A collaborative process can ensure that the review question and criteria are consistent with community identified needs and informed by the lived experience of Aboriginal and Torres Strait Islander communities. Through collaboration, consideration can be given to potential challenges that may be encountered in accessing information and support the early identification of strategies that could be implemented in the method.

For the enhanced method the authors co-produced the research questions with the Advisory Group, presenting a draft question and review protocol for discussion to clarify, enhance and deepen the relevance of the question. A workshop discussion defined the aim and objectives of the review and refinements were made as needed based on feedback and discussions with the Advisory Group. For example, to enhance the review question, the Advisory Group suggested that the question could be made more explicit and identified the need for a clear definition of a health care program as well as suggesting a depiction of the type of programs that definition would include.

#### 3. Identify relevant studies

The process of identifying relevant studies or searching requires a comprehensive strategy to achieve breadth and depth in the identification of primary studies, published and unpublished, suitable for answering the review question (Arksey & O'Malley 2005; Colquhoun et al. 2014; Levac, Colquhoun & O'Brien 2010). Practical decisions are made about the scope of the review, decisions justified, and limitations considered (Colquhoun et al. 2014; Levac, Colquhoun & O'Brien 2010). A team should be assembled at this stage with appropriate methodological and context expertise (Levac, Colquhoun & O'Brien 2010). Consistent with Indigenous methodologies, ways of knowing, being and doing must be embedded in all matters and contexts which concern Indigenous communities, from research to policy making and practice (Dudgeon, Kelly & Walker 2010). Searching can include electronic databases, reference lists, hand-searching of key journals and exploration of existing networks (Arksey & O'Malley 2005). The search itself can be consistent with the guidelines, with a search strategy implemented to identify peerreviewed publications and grey literature. In developing the search strategy, the expertise of the research team and the Advisory Group should be utilised to access key grey literature search engines (e.g. Australian Indigenous HealthInfoNet and The Lowitja Institute) relevant to Aboriginal and Torres Strait Islander health publishing (Thomson 2012; Tieman et al. 2014).

To integrate a partnership approach as part of the enhanced method, the Advisory Group informed the search strategy and supported identification of additional sources and key authors. This strategy enabled the identification of sources containing important data from a cultural and/or social perspective which would otherwise be left behind or excluded by relying solely on peer review and grey literature database searching or due to stringent criteria. In recognition of the many demands often placed upon community members and leaders this approach was highly flexible and consultations included email and face to face conversations to identify additional programs.

#### 4. Study selection

The scoping review method recommends the development of inclusion and exclusion criteria which are based on the review question (Peters et al. 2015). Study selection is an iterative process which involves searching the literature, refining the search strategy and

reviewing articles for inclusion (Levac, Colquhoun & O'Brien 2010). Levac et al (Levac, Colquhoun & O'Brien 2010) recommend that the criteria are reviewed and discussed by the team for consistency and that reviewers assess abstracts independently, with a process in place for a third reviewer to resolve any disagreement. As part of the iterative process, reviewer meetings can be held at the beginning, middle and end for clarifications, to discuss challenges or to refine search strategy or criteria if needed (Colquhoun et al. 2014).

When considering complex research questions or concepts for Indigenous research, Indigenous researchers with cultural knowledge and lived experiences are best placed to consider the nuances, complexities, histories and cultural understandings of phenomena that may not otherwise be understood (Martin-Mirraboopa 2003; Moreton-Robinson 2013; Rigney 1999; Smith 2012; Wilson 2008). For Indigenous populations or other population groups marginalised or harmed by previous research practices, the comprehensive cultural knowledge and understanding of the researcher not only contributes to quality, but also to safety for the population of interest (Ewen, Ryan & Platania-Phung 2019; Mohamed et al. 2021).

A scoping review aims to provide a broad overview or assist in mapping evidence and is not usually intended to produce a critically appraised and synthesised result or answer to a question (Munn et al. 2018). Therefore, critical appraisal is not required as part of the scoping review method but can be undertaken if it aligns with the scoping review aim (Munn et al. 2018). To ensure culturally relevant understandings specifically for Aboriginal and Torres Strait Islander populations an appraisal from a cultural perspective can be undertaken using *The Aboriginal and Torres Strait Islander Quality Appraisal Tool: appraising research quality from an Aboriginal and Torres Strait Islander perspective* (Harfield, Gibson, et al. 2020; Harfield, Pearson, et al. 2020) (Appendix 4.2).

For the enhanced method the study selection criteria were developed in collaboration with the Advisory Group and implemented to assess programs for eligibility. Reviewers included Indigenous researchers e.g. both Aboriginal and Torres Strait Islander researchers with cultural and contextual knowledge. This supported an objective process which was culturally grounded. Consistent with the method, the two reviewers met beforehand to discuss context and mutual understandings of the topic and/or question of interest and then were guided by the criteria to independently assess the studies for

inclusion. The utilisation of the quality appraisal tool as part of this described enhanced method was not specifically for study inclusion and as such is described in the charting the data stage below. The Advisory Group remained informed of potential refinements with advice sought for critical changes. The PRISMA diagram was presented to provide an opportunity for the review to be guided by their cultural knowledge and lived experience. These approaches honour in practice that Indigenous people are the experts about their own lives and empowering for all involved (Ewen, Ryan & Platania-Phung 2019; Harfield, Pearson, et al. 2020; Smith 2012; Wilson 2008).

#### 5. Charting Data

For included studies, data are charted according to elements such as the study population, type of intervention, outcome or measures (Arksey & O'Malley 2005). It is recommended that a data charting form, which will determine the variables to extract, should be developed collectively with the research team. This is an iterative process which allows for continually updating the form to include data if required (Levac, Colquhoun & O'Brien 2010). Scoping Review approaches which are seeking breadth can allow data of cultural and contextual relevance to be collected and included in a systematic way (Levac, Colquhoun & O'Brien 2010). The Aboriginal and Torres Strait Islander Quality Appraisal Tool introduced above in the study selection stage, can ensure charting of data which is relevant for Aboriginal and Torres Strait Islander questions of interest (Harfield, Gibson, et al. 2020; Harfield, Pearson, et al. 2020). The tool has utility not only for inclusion/exclusion purposes but to enhance cultural meaning and understandings relevant to the population of interest. The tool was developed specifically for the appraisal of literature reviewed for Aboriginal and Torres Strait Islander questions of interest. The questions in the tool are consistent with Aboriginal and Torres Strait Islander ways of knowing, being and doing and principles of Indigenous methodologies. The questions cover whether the research was a need or priority determined by the community, consultation and engagement, leadership and governance, community and cultural protocols. Questions also include, intellectual and cultural property rights, benefits, translation and whether the research was strengths-based and informed by an Indigenous research paradigm. Evidence indicates that research which is reflective of community values, priorities and perspectives can contribute to more relevant and meaningful outputs

for Aboriginal and Torres Strait Islander people with a greater potential for knowledge translation (Harfield, Gibson, et al. 2020).

The enhanced partnership approach was implemented with Advisory Group input into the extraction tool to ensure that information collected was relevant. A draft extraction tool was developed and included refinements based on feedback from the Advisory Group and throughout the process of data extraction. In charting the data, *The Aboriginal and Torres Strait Islander Quality Appraisal Tool* (Harfield, Gibson, et al. 2020) was utilised for the purpose of systematically assessing/reviewing and charting types of studies and features from a cultural perspective and this information was included as results.

#### 6. Collating, reporting and summarising the results

The analysis in scoping reviews, also described as collating or summarising results, often includes descriptive numerical summaries to describe the overall number of included studies and their characteristics (Levac, Colquhoun & O'Brien 2010). Reporting the results requires consideration of the intended outcome and then presenting findings in a way that is best able to do that. To enhance the process, it is recommended that the implications are considered within a broader context including for research, policy and practice (Bainbridge, Tsey, et al. 2015). Through the purposeful consideration of analyses there is a greater ability to have translation of results that inform further research, policy and practice (Levac, Colquhoun & O'Brien 2010). It is imperative that Indigenous communities have ownership and control over Indigenous knowledge and that communities are actively involved in giving meaning to data about them and planning for its use (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014). Using preliminary findings to consult with stakeholders can build on the evidence and offer a higher level of meaning, content expertise and perspectives (Levac, Colquhoun & O'Brien 2010).

Aboriginal and Torres Strait Islander communication styles, such as thoughtful, deep listening, thinking, reflecting and considering, are processes which may take time (Duke et al. 2021). Further, consideration should be given to the cultural responsibilities and community priorities of Advisory Group members, these factors can inform the approaches for engagement and capacity of Advisory Group members to engage with the

research project at any time (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014). Flexible approaches are required by the researcher to develop and maintain relationships with the community and key decision makers and leaders throughout the entire research cycle (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014). This enables an integrated and embedded approach to knowledge translation and the ability for research findings to influence policy and practice (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014; Wand & Eades 2008).

To integrate partnership approaches in this stage consultation occurred with the Advisory Group to determine how they would prefer for findings to be presented to them. Findings were synthesised with the Advisory Group through *Yarning*, an Indigenous approach to conversation which involves sharing stories and prioritising Indigenous communication processes (Bessarab & Ng'Andu 2010; Fredericks et al. 2011; Geia, Hayes & Usher 2013). Findings were prepared and presented in a range of mediums including slides, charts, graphs, tables, handouts (Bond, Foley & Askew 2016). The approach remained consistent with relationality and prioritising the knowledges of the Advisory Group through a 'workshop' style discussion to make sense of and give meaning to the results and to ensure they were accurate, representative and relevant to lived experiences. The Advisory Group informed strategy for the dissemination of the findings and strategic direction for how best to utilise the findings to influence systems, policy and practice change.

# 4.1.6 Implications for public health

Indigenous ways of knowing, being and doing are essential in research with
 Indigenous populations to ensure that research is of maximum benefit to the

community and can be translated into meaningful policy and practice changes which address the significant health inequities experienced.

- The existing scoping review methodology by Levac and colleagues (Levac, Colquhoun & O'Brien 2010) is enhanced by the incorporation of partnership approaches which are culturally relevant, relational, reciprocal and of benefit to populations and communities.
- Indigenous knowledge can strengthen non-Indigenous research methods across a range of research priorities and for populations who experience significant health inequities.

#### 4.1.7 Conclusion

Aboriginal and Torres Strait Islander communities have a long history with research. At times research has illuminated challenges facing communities while at the same time negatively impacting communities by continuing to create deficit discourses. In addition, research with Aboriginal and Torres Strait Islander communities is often undertaken within a non-Indigenous context utilising non-Indigenous methodologies and methods. The process of decolonising methodologies ensures that Aboriginal and Torres Strait Islander knowledge and expertise inform any research with Aboriginal and Torres Strait Islander communities.

A partnership approach to research with Aboriginal and Torres Strait Islander communities which is grounded in the establishment of mutual trust enables Aboriginal and Torres Strait Islander people to have an integral role in research for their communities (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; Dudgeon, Kelly & Walker 2010; Jamieson et al. 2012; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014; Wand & Eades 2008). The skills and knowledge of community are important resources in the research process, and consistent with partnership approaches, the balance of power resides with Aboriginal and Torres Strait Islander people (Australian Institute of Aboriginal and Torres Strait Islander Studies 2020; National Health and Medical Research Council 2018; South Australian Health and Medical Research Institute 2014). From the outset, a collaborative approach enables knowledge translation, benefit and impact to be planned for accordingly within the review.

Participatory approaches which centre consumer lived experiences in the research process has the potential to enhance the meaning, understanding and interpretation of research benefits for those it is intended to serve. The expansion of the scoping review method to prioritise Indigenous knowledges and expertise as well as the use of a culturally relevant appraisal influences research practice and translation for Aboriginal and Torres Strait Islander communities. Researchers who genuinely integrate the principles of Indigenous methodologies can avoid mistakes of the past, listen to and empower Indigenous communities and researchers to own, control and tell the stories of and for Indigenous people, as they always have.

#### **Declarations**

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#### Authors' contributions

TB implemented the enhanced method and prepared this manuscript. The Advisory Group were integral in the implementation of the method expansion and provided input into and reviewed this manuscript. AB, KC, NH and OP provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the enhancement and the writing of this manuscript.

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Addressing the Social Determinants of Indigenous Health Advisory Group

#### Authors' information

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A/Prof Odette Pearson is a Kuku Yalanji/Torres Strait Islander Platform Lead for Population Health in Wardliparingga Aboriginal Health Equity at the South Australian Health and Medical Research Institute and the University of Adelaide, Faculty of Health and Medical Sciences. Odette seeks to understand how institutional policies and practices drive health and social inequities experienced by Indigenous populations. Integral to her research is the inclusion of Aboriginal communities in defining their health and wellbeing and how Indigenous data can be governed in the future to derive greater benefit for the population.

A/Prof Kootsy Canuto is a Torres Strait Islander (Wagadagam Clan) and Aboriginal and Torres Strait Islander male health and wellbeing researcher at Flinders University, College of Medicine and Public Health. His research is predominantly with Aboriginal and Torres Strait Islander males focused on the utilisation of primary health care services and facilitating the co-design of social and emotional wellbeing programs.

Professor Alex Brown an Aboriginal medical doctor and researcher who over the last 20 years has established an extensive and unique research program focused on chronic disease in vulnerable communities. He leads projects encompassing epidemiology, psychosocial determinants of chronic disease, mixed methods health services research in Aboriginal primary care and hospital settings, and randomised controlled trials of pharmacological and non-pharmacological chronic disease interventions. His work has a particular focus on outlining and overcoming health disparities.

# 4.2 HEALTH PROGRAMS ADDRESSING THE SOCIAL DETERMINANTS OF HEALTH FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE: A SCOPING REVIEW

This section is formatted as a peer-review manuscript for submission:

Brodie T, Pearson O, Canuto K, Brown A, Howard NJ. (Draft). Health programs addressing the social determinants of health for Aboriginal and Torres Strait Islander people: a scoping review. Target Journal: Australian New Zealand Journal of Public Health.

# Statement of Authorship

| Title of Paper      | Health programs addressing the social determinants of health for Aboriginal and Torres Strait Islander people: a scoping review |
|---------------------|---|
| Publication Status  | ☐ Published ☐ Accepted for Publication ☐ Submitted for Publication Unpublished and Unsubmitted work written in manuscript style |
| Publication Details | Prepared for submission to the Australian New Zealand Journal of Public Health (ANZJPH).  |

# **Principal Author**

| Name of Principal Author (Candidate) | Tina Brodie  |  |  |  |  |  |  |
|--------------------------------------|--|--|--|--|--|--|--|
| Contribution to the Paper            | TB implemented the method and prepared this manuscript.  The Advisory Group chaired by the candidate were integral to the review described in this manuscript.   |  |  |  |  |  |  |
| Overall percentage (%)               | 60   |  |  |  |  |  |  |
| Certification:                       | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper. |  |  |  |  |  |  |
| Signature                            | Date 11 April 2023   |  |  |  |  |  |  |

## **Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate in include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

| Name of Co-Author         | Natasha Howard  |    |     |               |  |  |  |
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| Contribution to the Paper | NH provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the review as well as the writing of this manuscript. |    |     |               |  |  |  |
| Signature                 |   | Da | ate | 12 April 2023 |  |  |  |

| Name of Co-Author         | Odette Pearson  |      |               |
|---------------------------|---|------|---------------|
| Contribution to the Paper | OP provided leadership advice and guic conceptual design, the implementation of the manuscript. |      | 37.           |
| Signature                 |   | Date | 13 April 2023 |

| Name of Co-Author Kootsy Canuto |    |          |     |   |  |  |  |   |               |
|---------------------------------|----|----------|-----|---|--|--|--|---|---------------|
| Contribution                    | to | the Pape | con | KC provided leadership advice and guidance into the methodology, to conceptual design, the implementation of the review as well as the writing of the manuscript. |  |  |  | • |               |
| Signature                       |    |          |     |   |  |  |  | Date                                    | 11 April 2023 |

| Name of Co-Author |    |           | Alex Brown  |      |               |
|-------------------|----|-----------|---|------|---------------|
| Contribution      | to | the Paper | AB provided leadership advice and guid conceptual design, the implementation of the manuscript. |      | 0,7           |
| Signature         |    | <u> </u>  |   | Date | 12 April 2023 |

**Authors:** Tina Brodie, Natasha J. Howard, Odette Pearson, Kootsy Canuto and Alex Brown.

*Keywords*: Aboriginal and Torres Strait Islander, Social Determinants of Health, Health Equity, Health Programs, Primary Health Care, Aboriginal Community Controlled Health Organisations.

#### Abstract

#### **Objective**

Aboriginal and Torres Strait Islander people experience adverse outcomes on all indicators of health and social disadvantage, yet there is limited understanding of health programs which address the social determinants of health. This scoping review aimed to identify health programs addressing the social determinants of health for Aboriginal and Torres Strait Islander people and outline the extent that program delivery aligned with Aboriginal and Torres Strait Islander knowledges.

#### Method

Published review guidelines by *Levac et al* were enhanced to integrate Indigenous knowledge, expertise and engagement in each of the review stages (Brodie et al Under Review). A search strategy was implemented to identify peer-reviewed (MEDLINE) publications and grey literature papers. Selected studies were required to address a health need and reference one or more social determinant/s of health. Screening and inclusion were undertaken by two independent reviewers with cultural and content knowledge. Charted data were analysed by types of programs, delivery contexts and settings and how determinants were described and measured. A cultural appraisal was utilised to consider the quality of evidence from a cultural perspective, and Indigenous knowledge and ways of knowing were embedded as part of the review method and results.

#### Results

The search identified a total of 2469 sources, 32 papers were included for extraction after screening for eligibility as per the selection criteria. Evidence of cultural perspectives varied in relation to governance, engagement and leadership of included programs. Programs often made implicit and broad references to the social determinants such as addressing socio-economic factors and there were few programs which explicitly

addressed the social determinants of health, or included specific approaches, tools and measures.

#### **Conclusions**

This review provides a comprehensive culturally relevant understanding of programs addressing the social determinants of health within the health setting, for Aboriginal and Torres Strait Islander communities.

## Implications for public health

This review makes an important foundational contribution to the social determinants of health knowledge to practice action gap for Aboriginal and Torres Strait Islander populations and highlights the need to consistently name, label and measure the social determinants of health.

# 4.2.1 Background / Introduction

Aboriginal and Torres Strait Islander communities health status and outcomes are well established with an increasing focus on the importance of responding to holistic needs, in health service delivery (Dudgeon, Milroy & Walker 2014; Paradies et al. 2015; Raphael & Swan 1997; Swan & Raphael 1995). Social and emotional wellbeing describes the holistic approach to Aboriginal and Torres Strait Islander health and wellbeing and encompasses the interconnection of social, emotional, spiritual and cultural factors (National Aboriginal Health Strategy Working Party (NAHSWP) 1989). Broader social factors, known as the social determinants of health, are shaping social and emotional wellbeing and is estimated that 34% of the of the burden of disease for Aboriginal and Torres Strait Islander people can be attributed to the social determinants of health (Australian Institute of Health and Welfare 2020a; Dudgeon, Milroy & Walker 2014; Solar & Irwin 2010). However, approaches to health care provision in Australia and globally have been heavily influenced by biomedical approaches focused on responding to specific conditions within the body (Farre & Rapley 2017; Haynes et al. 2021). A focus on macro/intermediary determinants of health (Pearson et al. 2020; Solar & Irwin 2010) enables a shift from individual responsibility to societal and structural responsibility (Short & Mollborn 2015).

A range of reports and plans, including the most recent national Aboriginal and Torres Strait Islander health plan, clearly articulate the need for action on the social determinants of health and for these actions to be relevant to Aboriginal and Torres Strait Islander communities (Commonwealth of Australia 2017; Department of Health 2021; Verbunt et al. 2021). This increasing recognition of the social determinants of health in plans and policies has not yet equated to understandings of how these are applied in health care setting practice (Brodie et al. 2021; Fisher et al. 2016). Further, Pearson and colleagues (Pearson et al. 2020) found that Aboriginal Community Controlled Health Organisations 'do whatever it takes' to respond to the social determinants of health (Pearson et al. 2020). However, details of what is delivered are often not documented making understandings of current approaches to the social determinants of health in health care settings challenging (Pearson et al. 2020). An understanding of the health care system responses which have been implemented to address these determinants is needed.

This scoping review aims to identify health programs addressing the social determinants of health to inform understandings and practice approaches to address the social determinants of health as part of social and emotional wellbeing for Aboriginal and Torres Strait Islander people.

#### 4.2.2 Method

The Indigenous methodology was developed and implemented in Wardliparingga Aboriginal Health Equity (Wardliparingga) at the South Australian Health and Medical Research Institute (SAHMRI), Adelaide, South Australia. Wardliparingga engages with community in alignment with the principles outlined in the South Australian Aboriginal Health Research Accord to undertake research which is informed by community priorities and aligns with Aboriginal and Torres Strait Islander ways of knowing, being and doing (South Australian Health and Medical Research Institute 2014). A scoping review whilst systematic in its steps is flexible and supports accessing a breadth of information on a topic. The published review guidelines by Levac, Colquhoun and O'Brien (2010) were enhanced by Brodie et al. (Under Review) to align with an Indigenous methodology and embed a partnership through an Advisory Group. The details of these enhanced approaches are described in Brodie et al. (Under Review) and informed the following steps:

#### 1. Partnership

The first enhancement reconceptualises the stage of consultation to partnership. Levac, Colquboun and O'Brien (2010) identify consultation as a sixth optional step, however, as part of the method enhancement the integrated partnership approach is embedded in each of the review stages (Brodie et al. Under Review).

#### 2. Identify the research question

The review question 'What health services or programs intervene on a health need and address the social determinants of health of Aboriginal and Torres Strait Islander communities?' was co-produced with the Advisory Group through a collaborative process to ensure that the review question and subsequent review processes were consistent with community identified needs and informed by the lived experience of Aboriginal and Torres Strait Islander communities.

#### 3. Identify relevant studies

The search strategy aimed to find both peer-reviewed publications and grey literature. Ovid MEDLINE was utilised as it supported specific and advanced searching and accesses the same sources as PubMed and other major biomedical databases (Sladek et al. 2013). Medical subject headings (MeSH) and text words included:

- Aboriginal OR Indigenous OR Torres Strait Islander OR Oceanic Ancestry Group
- intervention OR program
- health care OR healthcare

The search was limited to articles published in English from 2008 until the date of the search in 2019. In 2007, the Australian Government committed to 'closing the gap' in life expectancy between Aboriginal and Torres Strait Islander and non-Indigenous Australians (Commonwealth of Australia 2018a). Additionally, in 2008, the World Health Organisation (WHO) released the "Closing the gap in a generation" report (WHO 2008). These significant milestones were the rationale for the time period selection, which aligns with various Government and policy changes to focus on the broader social determinants of health within Aboriginal and Torres Strait Islander health. Additionally, these year limits ensure programs have relevance to contemporary contexts and evidence-based practice.

A desktop internet-based search was completed of a range of key grey literature search engines relevant to Aboriginal and Torres Strait Islander health publishing including: Trove; Australian Indigenous HealthInfoNet; The Lowitja Institute; and Google. The grey literature search was informed by Olsan et al. (2011) guidelines which include search tools and techniques to manage the scope of the search, find and access information. Results from the internet-based search were limited to the first 10 pages.

As per the enhancement methodology consultation occurred with Advisory Group members and key experts, the listing of studies included through the peer-review and grey literature search were reviewed to identify additional sources and key authors, including unpublished reports and evaluations. The approach enabled the identification of sources difficult to retrieve through usual search methods. This approach facilitated access to programs that Advisory Group members and key experts had knowledge of as part of their professional expertise and lived experience as Aboriginal and Torres Strait Islander people. Any studies identified were collated and then reviewed to determine if they met the eligibility criteria as part of study selection. Lastly, the reference list of included studies was checked to identify any eligible papers.

#### 4. Study selection

The search criteria were developed in collaboration with the Advisory Group and reviewers included both an Aboriginal and a Torres Strait Islander researcher with cultural and content knowledge. The two reviewers met beforehand to discuss context and mutual understandings and then were guided by the criteria to independently assess the studies for inclusion. Studies identified through database searching were downloaded into Endnote X8 software (The EndNote Team 2019) and then imported into Covidence (Covidence systematic review software 2019). Two reviewers independently assessed studies for inclusion, the full text was retrieved for sources that could not be excluded based on title/abstract and reviewed by the two reviewers to confirm if they met the inclusion criteria. The grey literature selection process included recording identified studies into a log and then reviewing full text for inclusion before importing into Covidence. When more than one paper was identified for the same study, a decision was made to include the study which contained the most relevant information in relation to addressing the social determinants of health. If the two reviewers had differing opinions on inclusion, a third independent reviewer was consulted.

The Aboriginal and Torres Strait Islander Quality Appraisal tool (Harfield, Gibson, et al. 2020) was applied as part of the enhanced scoping review method to extract data from a cultural perspective valuing and prioritising Indigenous knowledge and ways of knowing as part of the review method and results. Whilst not required for a scoping review, Levac et al (2010) highlight there are benefits to applying quality appraisals in scoping studies depending on the review question. Brodie et al (Under Review) recommend for Aboriginal and Torres Strait Islander health research that any evidence synthesis consider the cultural relevance of the research using a culturally informed appraisal tool (Harfield, Gibson, et al. 2020) developed specifically for the appraisal of literature reviewed for Aboriginal and Torres Strait Islander questions of interest.

Reviewers were guided by the following criteria:

#### Participants/population

Programs were included if the participants included Aboriginal and/or Torres Strait Islander people, or the program/intervention was specific to Aboriginal and/or Torres Strait Islander people.

#### Context

Health programs were defined as those that intervene on a health need and are consistent with Aboriginal and Torres Strait Islander definitions of health. The program could address physical health and/or social and emotional wellbeing. The breadth of these health-related areas enabled the inclusion of programs across a range of areas where one or more social determinant domains were referenced. The focus for this review was not on the health need or outcome but rather the social determinant/s being addressed as part of the health program delivery. Programs could be delivered in the Australian health care system including state government, private, non-government and primary, secondary and tertiary settings. Health needs were defined using the Aboriginal and Torres Strait Islander Health Performance Framework (HPF) (Australian Health Ministers' Advisory Council (AHMAC) 2017). The HPF reports on a range of health priorities relevant to Aboriginal and Torres Strait Islander communities including chronic and infectious diseases, ear and eye health, mental health and emotional wellbeing (Table 4.2.1).

*Table 4.2.1: Health needs for scoping review inclusion* 

| Health Need Domain   | Health Needs for Study Inclusion                            |
|----------------------|---|
| Health condition     | Acute rheumatic fever and rheumatic heart disease,          |
|                      | cancer, circulatory disease, diabetes, high blood pressure, |
|                      | infectious diseases, injury and poisoning, kidney disease,  |
|                      | low birthweight, oral health, respiratory disease.          |
| Human functioning    | Community Function, disability, ear and eye health.         |
| Wellbeing            | Social and emotional wellbeing, mental health conditions    |
|                      | and substance abuse.  |
| Deaths and Mortality | Perinatal infant and child mortality, preventable death.    |

#### **Concept / Phenomena of Interest**

Programs were required to reference one or more social determinants of health. The WHO Commission on the Social Determinants of Health Conceptual Framework (Solar & Irwin 2010) and the HPF (Australian Health Ministers' Advisory Council (AHMAC) 2017) were used to conceptually align the social determinants of health which would be included (Table 4.2.2). The HPF for the most part is consistent with the WHO Commission on the Social Determinants of Health Conceptual Framework (Solar, O. & Irwin, A. 2010). This framework has been internationally recognised to be relevant across all cultures (Solar &

Irwin 2010). However, to date there has been few in-depth explorations of what constitutes the social determinants of health for Aboriginal and Torres Strait Islander communities specifically, or how these are interconnected and inter-related with cultural determinants. In the absence of such understandings these existing frameworks have been utilised, recognising these may have further considerations or limitations for Aboriginal and Torres Strait Islander communities.

Table 4.2.2: Alignment of HPF Determinants of health with WHO Conceptual Framework

| WHO Framework                       | HPF Determinant                          |  |
|-------------------------------------|--|--|
| Socio-economic position and context | Community Capacities                     |  |
| Social class, gender, and ethnicity | Community safety                         |  |
|                                     | Contact with the criminal justice system |  |
|                                     | Child protection                         |  |
|                                     | Transport                                |  |
|                                     | Indigenous people with access to their   |  |
|                                     | traditional lands                        |  |
| Education                           | Scio-economic factors:                   |  |
|                                     | Education participation and outcomes     |  |
| Occupation                          | Socio-economic factors:                  |  |
|                                     | Employment                               |  |
| Income                              | Socio-economic factors: Income           |  |
| Living and Working Conditions       | Environmental Factors: Housing           |  |
| Health System                       | Health System Performance: Access        |  |
|                                     |  |  |
| Behaviors, biological and           | Health behaviors and person related      |  |
| psychosocial factors                | factors                                  |  |
|                                     |  |  |

Health behaviors and person-related factors while identified as determinants of health in the HPF, were excluded to align with the focus of this review on the broader structural and intermediary socio-economic and social determinants which shape behaviors, rather than the behaviors themselves (Short & Mollborn 2015). This was also the rationale for the inclusion of Health System Access which is a stand-alone component of the HPF and not described as a determinant of health (Australian Health Ministers' Advisory Council

(AHMAC) 2017). Additionally, housing is often referred to as both an environmental and social determinant of health, for the purpose of this review was included as a social determinant as per the Mansour et al. (2022) glossary.

The inclusion criteria were broad to allow for varied definitions of the social determinants of health, references could be implicit with Lucyk and McLaren (2017) accounting for this same phenomenon in a 2017 scoping review of the social determinants (Lucyk & McLaren 2017). Social determinants could be referred to using a range of keywords as part of the inclusion process for each of the social determinant domains, including; housing, socio economic factors (education, employment, income), community capacities (connection to Country, community safety, child protection, justice system and transport), and health system access (Table 4.2.3).

Table 4.2.3: Determinants for scoping review inclusion

| Social Determinant of<br>Health | Keywords   |  |
|---------------------------------|--|--|
| Cultural Connection             | Access to traditional lands, connection to Country and     |  |
|                                 | cultural identity.   |  |
| Education                       | Training, formal education and schooling, school           |  |
|                                 | attendance and professional development.                   |  |
| Employment                      | Unemployment, pre-employment and work readiness or         |  |
|                                 | development programs                                       |  |
| Income                          | Low income, poverty, finance, money, financial literacy    |  |
|                                 | and income support, food security as well as subsidised    |  |
|                                 | health care programs or subsidised nutrition programs.     |  |
| Housing                         | Homelessness, accommodation, overcrowding, safety,         |  |
|                                 | security and stability.                                    |  |
| Health System Access            | Access to services, responsiveness of services,            |  |
|                                 | connection to services, workforce development and          |  |
|                                 | transport where it was for enabling access to a particular |  |
|                                 | health service.  |  |

Programs that included broad references to addressing social factors and socio-economic conditions were defined as 'no primary determinant identified' (Lucyk & McLaren 2017). There were no study type restrictions and any primary research studies and evaluations including quantitative, qualitative and mixed-methods were included. Systematic

reviews, meta-analysis and other non-primary research studies were hand searched to identify relevant primary studies for inclusion.

#### 5. Charting Data

An extraction tool was developed to systematically chart health care program features. The extraction tool was refined in partnership with the Advisory CGroup to ensure that information to be extracted was relevant and useful. Included papers were reviewed to identify and document the program name, characteristics and delivery features as well as the social determinant addressed including measures or outcomes, where reported. The extracted features included:

- Context: The service delivery context in which the program was provided including State Government, Aboriginal Community Controlled Health Organisations (ACCHO) and Non-Government Organisations (with the exception of ACCHOs).
- Setting: The location in which the primary activities were undertaken for the
  program including community (community centre, organisation or other
  community location), clinic, home, hospital, mobile health clinics, tele-health
  services and multiple settings which included combinations of home / clinic /
  hospital or community.
- Primary health need identified: Based on the health performance framework measures described in detail in the eligibility criteria.
- Target population: The specific target population within the Aboriginal and Torres Strait Islander population.
- Discipline: The discipline/s delivering the program including multi-disciplinary (one or more of the following); Medical practitioners, Aboriginal Health Worker and Other.
- Social determinant of health: Broadly defined as social needs and could include housing, education, employment, transport, cultural connection and identity and access to services.

- Implicit or Explicit: Implicit programs referenced but did not explicitly define the social determinants of health and explicit programs included direct references to the social determinants of health.
- Cultural Appraisal: A range of questions which assess whether the research was a
  need or priority determined by the community, had adequate consultation and
  engagement, leadership and governance, protocols, rights, intellectual and
  cultural property rights, benefits, translation and whether the research was
  strengths-based and informed by an Indigenous research paradigm.

## 6. Results

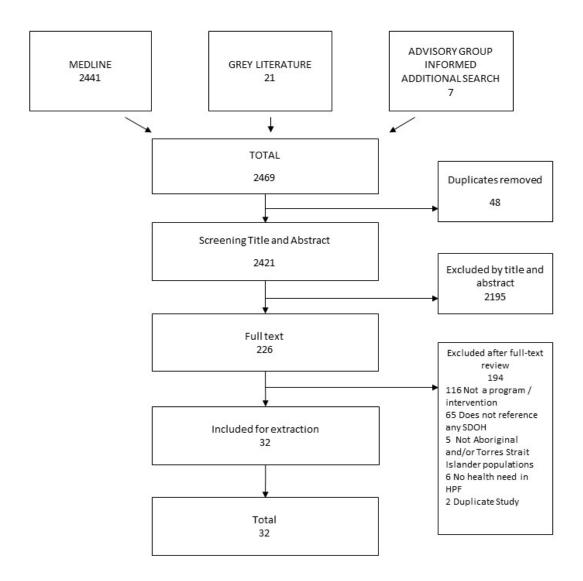
Data were charted in Microsoft Excel for Windows 365 (Microsoft Corporation 2022a) and then imported into IBM SPSS Statistics for Windows, Version 27 (IBM Corp. 2010) for analysis. Frequencies and descriptors were extracted from SPSS and provided to the Advisory Group who were involved in the synthesis of findings to ensure they were accurate, representative and have a practical utilisation. This process enhanced the interpretation and understanding of the findings and the group was able to support planning for the next steps and the translation of the results.

# 4.2.3 Results

The Ovid MEDLINE search was completed in February 2019, grey literature searching March 2019 and additional searching in June 2019 with the search complete in June 2019.

Ovid MEDLINE identified 2441 sources, 21 sources identified as part of the grey literature search and 7 as part of the additional searching (with Advisory Group and key experts). A total of 2469 sources were screened for eligibility as per the selection criteria (Figure 4.2.1).

Figure 4.2.1: PRISMA Flow Diagram



# Program Characteristics

A summary of included programs and key characteristics is attached (Appendix 4.3). Programs were provided primarily by State Government (40.6%) and Aboriginal Community Controlled Health Services (28.1%) in a range of settings which included a combination of home, clinic, hospital, and community. Programs were delivered in the ACT (1), NSW (7), NT (6), QLD (7), SA (2) and WA (7) and the majority were provided in remote and very remote locations (Table 4.2.4).

Table 4.2.4: Program characteristics by context, setting and location

| Context   | n  | %    |
|---|----|------|
| State Government                                    | 13 | 40.6 |
| Aboriginal Community Controlled Health Organisation | 9  | 28.1 |
| Non-government organisation                         | 2  | 6.3  |
| Undetermined  | 8  | 25.0 |
| Setting   | n  | %    |
| Community   | 10 | 31.3 |
| Clinic  | 3  | 9.4  |
| Home  | 1  | 3.1  |
| Hospital  | 0  | 0    |
| Mobile  | 2  | 6.3  |
| Multiple  | 12 | 37.5 |
| Telehealth  | 1  | 3.1  |
| Undetermined  | 3  | 9.4  |
| Geographic Location                                 | n  | %    |
| Urban   | 8  | 25.0 |
| Regional  | 4  | 12.5 |
| Remote and Very Remote                              | 13 | 40.6 |
| State-wide  | 5  | 15.6 |
| Multiple  | 2  | 6.3  |

# Social Determinant of Health Addressed

Only 50% of the relevant social determinants of health domains were charted as being addressed within a health program including, cultural connection, education, housing, health system and income. A remaining five social determinants of health domains were not charted during extraction, and included: child protection, community safety, employment, justice system and transport.

A total of 32 programs addressed one or more social determinants of health domains. There were 13 programs which related to health system access, and of these programs 84.6% (n=11) were in specific to health care access. Of interest, 10 programs did not specify a primary determinant of health, instead referring only to 'social factors' as a broader construct (Figure 4.2.2).

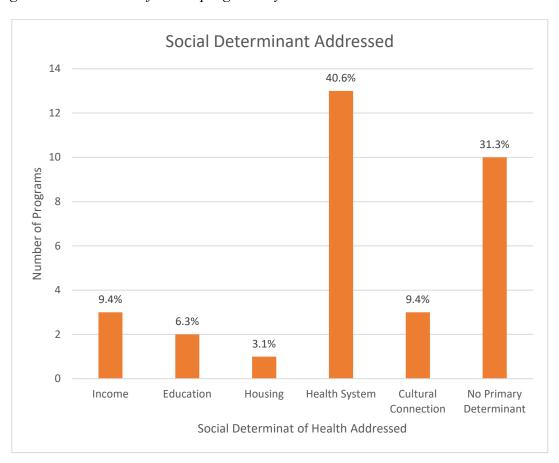


Figure 4.2.2: Number of health programs by social determinant domain addressed

State Government responsible for providing the greatest proportion, 46.1% (n=6) of programs for the health system domain (Figure 4.2.3).

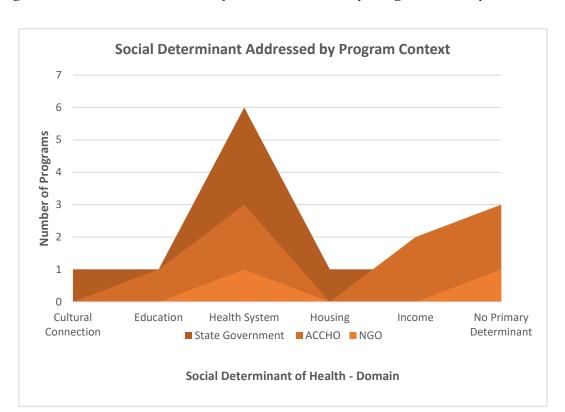


Figure 4.2.3: Social Determinant of Health Addressed by Program Delivery Context

Of included programs, 45.1% implicitly referenced the social determinants of health. Implicit references were subtle or indirect references and examples of these type of statements included "Many Indigenous residents experience socioeconomic disadvantage with low levels of skills occupations, high rates of unemployment and low incomes" (McCalman et al. 2015) and "The [program] Facilitated engagement of women and their families with the health system" (McCalman et al. 2015).

Programs that were explicit in describing or referring to the social determinants of health consistently had an explicit intention, with 54.9% of programs explicitly identifying and describing the intention or making statements about the relationship between the health outcome and the social determinant/s of health. Of programs with Aboriginal and Torres Strait Islander Governance, 58.3% were more explicit when describing the social determinants of health, compared to implicit approaches articulated by those without or with unclear Aboriginal and Torres Strait Islander governance (41.6% of programs).

Explicit programs made specific and clear comments about the social determinant of health.

<sup>&</sup>quot;[the program] was intentionally designed .. recognition of the array of social determinants of Aboriginal health and wellbeing" (Vallesi et al. 2018). and;

"The role of the Aboriginal Community Workers is primarily to ensure cultural safety and support community engagement, and assist in addressing social determinants."

(Zarnowiecki et al. 2018)).

# Program Delivery Features

Programs were delivered across health needs including Health Conditions (34.4%), Human Function (15.6%), Wellbeing (12.5%) and programs addressed specific health needs as well as multiple identified health needs (37.5%). This category included programs which addressed more than one primary health need, for example a chronic condition and social and emotional wellbeing (Figure 4.2.4).



Figure 4.2.4: Primary Health Need identified

# Target Population

Programs were delivered to a range of participants with eight programs (25.0%) which had an Aboriginal and Torres Strait Islander population approach. There were 24 (75.0%) programs being delivered to specific target groups within the Aboriginal and Torres Strait Islander population. Of these 24 programs, target groups included women children and families (66.7%), adolescents (8.3%), disability and elderly (8.3%) and 16.7% targeted to specific health needs. Of the 16 programs for Aboriginal Women, Children and Families, 43.8% (n=7) of these were maternal health/ante-natal/birthing programs, 18.8% (n=3) were parenting programs and the remaining 37.5% (n=6) were women's/family wellbeing.

# Discipline (Delivered by)

Programs were delivered by a range of disciplines, 53.1% (n=17) were multi-disciplinary and 70.5% (n=12) of multi-disciplinary programs included combinations of Aboriginal Health Workers and Medical Practitioners.

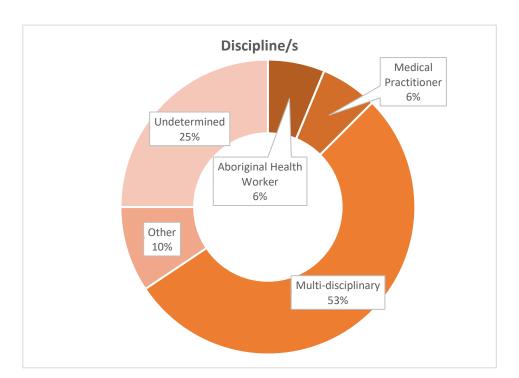


Figure 4.2.5: Discipline/s Delivering Health Programs

# Cultural Appraisal

Results of the appraisal of the quality of evidence from an Aboriginal and Torres Strait Islander perspective are detailed in Table 4.2.5. Programs which responded to a need or priority (71.9%), included consultation and engagement (56.3%), and governance (37.5%) made statements such as; "..local Aboriginal community members were concerned that.." (Bertilone & McEvoy 2015) highlighting implicitly that the approach was in response to community concern. Responses were also more explicitly stated within the manuscript findings and examples include; "the program was developed in consultation with Aboriginal women and health workers.." (Kildea et al. 2017) and "A collaborative approach was used in which key stakeholders ([program] workers, interested community members, Departmental and other organisational staff) were involved in framing the methodology" (Kildea et al. 2017).

Table 4.2.5: The Aboriginal and Torres Strait Islander Quality Appraisal Tool Results

| Question  | Υe | es   | Par | tially | Unclear |       |
|---|----|------|-----|--------|---------|-------|
|   | N  | %    | N   | %      | N       | %     |
| Q1. Did the research respond to a need or priority determined by the community?   | 23 | 71.9 | 3   | 9.4    | 6       | 18.8  |
| Q2. Was community consultation and engagement appropriately inclusive?  | 18 | 56.3 | 1   | 3.1    | 13      | 40.6  |
| Q3. Did the research have Aboriginal and Torres Strait Islander research leadership?  | 5  | 15.6 | 1   | 3.1    | 26      | 81.3  |
| Q4 Did the research have Aboriginal and Torres Strait Islander governance?  | 12 | 37.5 | 3   | 9.4    | 16      | 50.0  |
| Q5. Were local community protocols respected and followed?  | 19 | 59.4 | 1   | 3.1    | 12      | 37.5  |
| Q6. Did the researchers negotiate agreements in regard to rights of access to existing Aboriginal and Torres Strait Islander peoples' intellectual and cultural property?     | 0  | 0.0  | 0   | 0.0    | 32      | 100.0 |
| Q7. Did the researchers negotiate agreements to protect the intellectual and cultural property of Aboriginal and Torres Strait Islander peoples created through the research? | 0  | 0.0  | 0   | 0.0    | 32      | 100.0 |
| Q8. Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?                                  | 0  | 0.0  | 1   | 3.1    | 31      | 96.9  |
| Q9. Was the research guided by an Indigenous research paradigm?   | 7  | 21.9 | 5   | 15.6   | 20      | 62.5  |
| Q10. Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?          | 15 | 46.9 | 7   | 21.9   | 10      | 31.3  |
| Q11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?  | 16 | 50.0 | 9   | 28.1   | 7       | 21.9  |
| Q12. Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?   | 19 | 59.4 | 5   | 15.6   | 8       | 25.0  |
| Q13. Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?   | 12 | 37.5 | 4   | 12.5   | 16      | 50.0  |
| Q14 Did everyone involved in the research have opportunities to learn from each other?  | 13 | 40.6 | 2   | 6.3    | 17      | 53.1  |

# 4.2.4 Discussion

The findings of this review highlight inconsistencies in describing the social determinants of health. Thirty per-cent of programs included in this review did not address a primary determinant and instead referred broadly to socio-economic circumstances or social conditions, highlighting the various ways in which the determinants are defined and described (Lucyk & McLaren 2017). This is consistent with research which has highlighted inconsistencies in conceptual models, frameworks and descriptions of the social determinants of health (Lucyk & McLaren 2017). Health programs addressing the social determinants of health are not clearly defining, describing or reporting social determinants of health. This gap has likely been influenced by the complexity of the social determinants of health and the diverse social and cultural needs of Aboriginal and Torres Strait Islander communities (Osborne, Baum & Brown 2013). There are no consistent definitions, there is no shared language or understanding, the social determinants are described in a range of ways including the highly implicit nature in which determinants are described. These are all factors which contribute to challenges in being able to measure the social determinants of health and inform practice in action on these determinants and their role in shaping health outcomes.

# Who is addressing the social determinants of health?

The context provides insights into the types of services currently addressing the social determinants of health in health service provision to Aboriginal and Torres Strait Islander communities. State Government agencies including primary health care and hospital services, as the major provider of most health and social services to Aboriginal and Torres Strait Islander Communities, represent a high proportion of the programs addressing the social determinants of health. Aboriginal Community Controlled Health Organisations (ACCHO) are also taking a primary role in addressing the social determinants of health. This is consistent with the large proportion of programs provided in rural and remote areas where ACCHOs are often primary service providers (Panaretto et al. 2014). Additionally, there is a concerted focus in Aboriginal and Torres Strait Islander health to ensure access to services in remote areas, and review findings highlighted Health System as the most common social determinant addressed. Health system programs were predominantly aimed at increasing access which is crucial for the provision of equitable and high quality health services regardless of demographic and/or socio-economic status (Boxall & Leeder 2006). Aboriginal and Torres Strait Islander people continue to report

various difficulties in accessing services including services not being available when needed, as well as transport difficulties and barriers due to costs (Ware 2013). Forty percent of included programs targeted access to the health system. Many of the programs included in the review addressed multiple health needs across the health domains, such as health conditions and social and emotional wellbeing, indicating higher rates of holistic approaches. This is consistent with Aboriginal and Torres Strait Islander views of health which include holistic social emotional wellbeing (National Aboriginal Health Strategy Working Party (NAHSWP) 1989).

# Flexible inter-disciplinary approaches

The review findings have highlighted that program delivery regarding the social determinants of health is flexible across a breadth of settings requiring flexible and accessible service provision diverse settings. High rates of programs in community or multiple settings indicates that these types of programs are often flexible in nature, consistent with the evidence which has identified that flexible implementation promotes increased access and engagement with programs (Hunt 2013; Morley 2015). Programs were also provided in hospitals, and in most instances, included other settings such as an ACCHO, or Aboriginal and Torres Strait Islander primary health care service.

Whilst health systems increasingly recognise the need to respond to the social determinants of health, their complex nature requires collaborations and responses across health and social services (Andermann 2016; Andermann 2018; Bambra et al. 2010). Multi-disciplinary practice is considered to enable coordinated and responsive care planning which is able to meet a range of needs (Benagiano & Brosens 2014). Multi-disciplinary approaches provide a promising start for addressing the social determinants of health which requires coordinated and inter-sectoral engagement across all determinant domains (Osborne, Baum & Brown 2013). It is not evident in the review findings that these inter-sectorial approaches currently exist, however the integrated and collaborative nature in which multiple disciplines are working together to address the social determinants of health highlights there is potential to build towards inter-sectorial engagement and collaboration to address the social determinants of health (Baum, Legge, et al. 2013). A potential limitation of this review in capturing inter-sectorial approaches is that programs were required to address a health need with programs that did not report

or describe a health need or outcome excluded. There was a purposeful intent to focus on how health care programs are addressing the social determinants of health and consequently inter-sectoral social programs which may have upstream impacts on health outcomes were not captured unless they were specifically addressing a health need as identified in the inclusion criteria.

# Types of action on the social determinants of health

Education supports health and economic outcomes through increased health literacy, access to services and employment opportunities (Tsey 1997). There were two programs (Alperstein & Dyer 2012; Jersky et al. 2016) which included education, one was provided through an early childhood education facility and the other program facilitated access to education for participants, with many participants experiencing successful educational outcomes among other health responses as part of the program.

Housing conditions have been well evidenced as fundamental to health, with crowded housing contributing to a range of health conditions (Bailie & Wayte 2006). The program which addressed housing was in relation to living conditions and the importance of functional and suitable housing. However, there were no programs addressing over-crowding or homelessness which are significant challenges currently experienced by Aboriginal and Torres Strait Islander communities (Australian Institute of Health and Welfare 2019).

Transport supports people to engage in education, employment andincreases access to health care, goods and services (Battellino 2009), despite this there were no health programs which identified access to driving programs, drivers' licences and/or public transport. Where transport was referenced, this was generally in relation to supporting access to health services and consequently these were recorded under health system access.

Employment and Income (financial security and financial resources) enhance wellbeing by increasing social capital, reducing chronic stress and supporting access to basic needs such as medication and nutritious food which support health and wellbeing (Carson et al. 2007). There were no programs in relation to employment. There were two programs which included income in the form of provision of financial incentives to engage in health care (Biggs, Walsh & Ooi 2016) or to provide financial subsidies to access fresh fruits

and vegetables (Black et al. 2013). No studies were identified for housing, transport and employment despite their identification as priority needs and measures in the health performance framework (Australian Health Ministers' Advisory Council (AHMAC) 2017).

# The Cultural Determinants of Health

The cultural determinants of health and wellbeing have been clearly articulated more recently in health plans and frameworks (Department of Health 2021; Williamson, Dent & Bowman 2021). At the time of this review the health performance framework measured connection to Country through access to traditional lands and was operationalised in this review as 'Cultural Connection'. Of the programs included for Cultural Connection, two of the programs looked at the benefits and importance of going on Country and one program focussed on the provision of health care on Country. The important role of cultural connection in health and wellbeing for Aboriginal and Torres Strait Islander people is increasingly being recognised (Verbunt et al. 2021). Connection to family, community, Country and cultural identity contribute to positive states of wellbeing (Kingsley et al. 2013; Verbunt et al. 2021). This was not reflected in the findings of this review with only three (Burgess 2008; Conway et al. 2018; David 2018) of 32 programs addressing this domain. The position and use of this measure in the HPF tends to conflate cultural determinants with other determinants of health and does not clearly articulate these as cultural determinants of health. It is necessary for a clearer articulation in research, policy and reporting which is community driven and more accurately reflects cultural understanding (Williamson, Dent & Bowman 2021). The underpinning Indigenous methodology of this review has supported culturally relevant understandings and contributes to findings which have relevance to the lived experiences of Aboriginal and Torres Strait Islander peoples.

# Implications for Public Health

• The review findings highlight the need for a call to action to name, label and measure the social determinants of health in health service delivery and research with Aboriginal and Torres Strait Islander people and communities.

- Implementation of the enhancement of the Scoping Review method to incorporate Indigenous knowledge and the inclusion of cultural appraisal of evidence to influence accountability and quality in Aboriginal and Torres Strait Islander health research. The cultural appraisal findings indicate there are highly varied ways in which research with Aboriginal and Torres Strait Islander communities is evidenced from a cultural perspective and that consideration of factors that would contribute to high quality research with communities are not always present in research projects or are not reflected in the publication of papers or research findings.
- For public health and health research more broadly, there is a need for increased transparency with evaluation findings to be made more readily available where appropriate for practice, policy and future research. This review relied on 'publicly' available and published evidence. As a result, there may be programs addressing the social determinants of health for Aboriginal and Torres Strait Islander communities which are not accessible to the public and therefore this information not available for the review.

# 4.2.5 Conclusion

Despite the international evidence on the role of the social determinants on health outcomes, the findings of this review highlight that there are limited health programs which address the social determinants of health for Aboriginal and Torres Strait Islander communities that measure impact on health outcomes. Programs which do address the social determinants of health tended to be flexible, interdisciplinary, implemented across multiple settings and those delivered by ACCHOs made up a significant portion of reviewed programs. This review provides a comprehensive culturally relevant understanding of the existing evidence in health for addressing the social determinants of health and provides the foundation to inform the development and implementation of practice action on the social determinants of health, including the need for clearer articulation of social of determinants of health measures within health programs. The findings enhance culturally relevant understandings about health programs addressing the social determinants of health, through a method which integrates Indigenous knowledges and considers important factors relevant to program delivery for Aboriginal and Torres Strait Islander communities.

# CHAPTER 5: CULTURAL PATHWAYS PROGRAM EVALUATION

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# **PRELUDE**

The South Australian Aboriginal and Torres Strait Islander community through extensive consultations (King & Brown, 2015) consistently expressed the need to respond to the social determinants of health as part of holistic health and wellbeing. This is consistent with *Chapter Three* findings which highlighted that South Australian Aboriginal and Torres Strait Islander communities experience significant inequalities for all social factors. The Cultural Pathways Program is a response to these community identified needs, designed and led by Aboriginal and Torres Strait Islander people and informed by holistic views of health. The program is implemented by Wardliparingga Aboriginal Health Equity Theme (Wardliapringga), at the South Australian Health and Medical Research Institute (SAHMRI) funded by Wyatt Benevolent Institution.

In partnership with Aboriginal and Torres Strait Islander communities, health organisations, experts in Type 2 Diabetes (T2D) and genomics, Wardliparingga has established a large population-based prospective cohort of Aboriginal and Torres Strait Islander adults across South Australia. The Predicting Renal, Ophthalmic and Heart Events in the Aboriginal Community (PROPHECY) study is known as and referred to throughout this thesis as the Aboriginal Diabetes Study (ADS). The objective of the ADS is to better understand the burden, history and potential for complication development in Aboriginal and Torres Strait Islander people with or at risk of T2D. ADS aims to understand and outline the social, psychological, environmental, clinical and genomic predictors of disease and disease progression. The study cohort involves 1390 participants from metropolitan, regional and remote settings with data collected on clinical, psychosocial, pathological and genomic outcomes, exposures and traits. Through implementation of ADS it became evident that there was a need not just to document, but to address the significant unmet social and cultural needs experienced by participants, in response the Cultural Pathways Program was developed.

The Cultural Pathways Program aims to identify the social and cultural needs of Aboriginal and Torres Strait Islander people, supporting empowerment of individuals and services to act on the determinants of health. Findings from the scoping review of health programs addressing the social determinants of health (*Chapter Four*) identified that there are few programs which specifically aim to address the social determinants of health, highlighting a significant practice evidence gap. This two-part chapter details the development, implementation and evaluation of the program led by the researcher. A detailed program

protocol (Appendix 5.1) and data collection instruments (Appendix 5.2) are provided as Appendices and are referenced where relevant throughout the chapter.

The aim of the evaluation was to understand the implementation process including what was delivered, how it was implemented and the experiences of program participants. The evaluation through reflective and formative methods supports further understanding on the interactions between Facilitators, program participants and the broader health and social service contexts through service connections. The evaluation has two main objectives:

Chapter 5.1 describes the Cultural Pathways Program approach and implementation of strengths-based practice as an accepted manuscript published in *Primary Health Care Research & Development*. The published open access version has been attached in Appendix 5.3.

Chapter 5.2 describes the implementation processes and participant/facilitator experiences of the Cultural Pathways Program and is structured in a Chapter format.

# 5.1 STRENGTHENING APPROACHES TO RESPOND TO SOCIAL AND EMOTIONAL WELLBEING NEEDS OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE: THE CULTURAL PATHWAYS PROGRAM

This section is formatted as a published manuscript:

Brodie T, Pearson O, Cantley L, Cooper P, Westhead S, Brown A, Howard NJ. (2021) Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the Cultural Pathways Program. Prim Health Care Res Dev. 2021 Jun 29;22:e35. doi: 10.1017/S1463423621000402. PMID: 34184630; PMCID: PMC8278791

# Statement of Authorship

| Title of Paper      | Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the Cultural Pathways Program   |  |  |  |  |
|---------------------|---|--|--|--|--|
| Publication Status  | ✓ Published  Accepted for Publication   |  |  |  |  |
|                     | Submitted for Publication  Unpublished and Unsubmitted work written in manuscript style   |  |  |  |  |
| Publication Details | Brodie T, Pearson O, Cantley L, Cooper P, Westhead S, Brown A, Howard NJ. Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the Cultural Pathways Program. Prim Health Care Res Dev. 2021 Jun 29;22:e35. doi: 10.1017/S1463423621000402. PMID: 34184630; PMCID: PMC8278791. |  |  |  |  |

# **Principal Author**

| Name of Principal Author (Candidate) | Tina Brodie  |      |               |  |  |  |
|--------------------------------------|--|------|---------------|--|--|--|
| Contribution to the Paper            | TB led the development and implementation of the program approach and evaluation described in this manuscript as well as activities associated with developing and writing this manuscript.  |      |               |  |  |  |
| Overall percentage (%)               | 55   |      |               |  |  |  |
| Certification:                       | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper. |      |               |  |  |  |
| Signature                            |  | Date | 11 April 2023 |  |  |  |

# **Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate in include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

| Name of Co-Author         | Odette Pearson  |  |      |               |  |  |  |
|---------------------------|---|--|------|---------------|--|--|--|
| Contribution to the Paper | OP provided leadership advice and guidance into the development and implementation of the program described in this manuscript. |  |      |               |  |  |  |
| Signature                 |   |  | Date | 13 April 2023 |  |  |  |

| Name of Co-Author         | Luke Cantley  |
|---------------------------|---|
| Contribution to the Paper | LC implemented the program approach with participants and supported the development of the program protocol which underpinned program implementation. |
| Signature                 | Date 17 April 2023  |

| Name of Co-A          | Author |     | Peita Cooper                            |     |      |              |     |  |
|-----------------------|--------|-----|---|-----|------|--------------|-----|--|
| Contribution<br>Paper | to     | the | PC implemented the development of the p | . 0 |      | •            | • • |  |
| Signature             |        |     | _                                       |     | Date | 13 April 202 | 23  |  |

| Name of Co-A          | Author |     | Seth Westhead            |  |                    |              |                                  |
|-----------------------|--------|-----|--------------------------|--|--------------------|--------------|----------------------------------|
| Contribution<br>Paper | to     | the | SW informe<br>this manus |  | ent of the screeni | ng tool util | ised in the program described in |
| Signature             |        |     | ]                        |  |                    | Date         | 11 April 2023                    |

| Name of Co-Author     |    |     | Alex Brown* Joint senior Authorship  |                               |
|-----------------------|----|-----|--|-------------------------------|
| Contribution<br>Paper | to | the | AB provided leadership advice and guidance into the d of the program described in this manuscript. | evelopment and implementation |
| Signature             |    |     | Date   | 12 April 2023                 |

| Name of Co-Author     |     | Natasha Howard*Joint senior Authorship  |            |                               |
|-----------------------|-----|---|------------|-------------------------------|
| Contribution to Paper | the | NH provided leadership advice and guidance of the program described in this manuscript. | into the d | evelopment and implementation |
| Signature             |     |   | Date       | 12 April 2023                 |

# 5.1.1 Abstract

Aboriginal and Torres Strait Islander holistic health represents the interconnection of social, emotional, spiritual and cultural factors on health and wellbeing. Social factors (education, employment, housing, transport, food and financial security) are internationally described and recognised as the social determinants of health. The social determinants of health are estimated to contribute to 34% of the overall burden of disease experienced by Aboriginal and Torres Strait Islander people. Primary health care services currently 'do what it takes' to address social and emotional wellbeing needs, including the social determinants of health, and require culturally relevant tools and processes for implementing coordinated and holistic responses. Drawing upon a research-setting pilot program, this manuscript outlines key elements encapsulating a strengths-based approach aimed at addressing Aboriginal and Torres Strait Islander holistic social and emotional wellbeing.

The Cultural Pathways Program is a response to community identified needs, designed and led by Aboriginal and Torres Strait Islander people and informed by holistic views of health. The Program aims to identify holistic needs of Aboriginal and Torres Strait Islander people as the starting point to act on the social determinants of health. Facilitators implement strengths-based practice to identify social and cultural needs (e.g. cultural and community connection, food and financial security, housing, mental health, transport), engage in a goal setting process and broker connections with social and health services. An integrated culturally appropriate clinical supervision model enhances delivery of the program through reflective practice and shared decision making. These embedded approaches enable continuous review and improvement from a program and participant perspective. A developmental evaluation underpins program implementation and the proposed culturally relevant elements could be further tailored for delivery within primary health care services as part of routine care to strengthen systematic identification and response to social and emotional wellbeing needs.

**Keywords:** Aboriginal and Torres Strait Islander, Social and Emotional Wellbeing, Social Determinants of Health, Case Management, Evidence-based practice, Primary Health Care.

# 5.1.2 Introduction

Aboriginal and Torres Strait Islander knowledge and wisdom has long recognised the role of social and cultural factors on health and wellbeing (Bartlett & Boffa 2001)). Aboriginal and Torres Strait Islander holistic health philosophy describes social and emotional wellbeing as the interconnection of social emotional, spiritual, cultural factors on health and wellness of not just individuals but communities (NAHSWP 1989). Social and emotional wellbeing as conceptualised by Gee et al (Dudgeon, Milroy & Walker 2014) recognises the ongoing influence of historical, political and social factors on health and social outcomes (Dudgeon, Milroy & Walker 2014; Paradies et al. 2015; Raphael & Swan 1997; Swan & Raphael 1995). These social factors (employment, education, housing, income and transport) are internationally described and recognised as the social determinants of health and are estimated to contribute 34% of the overall burden of disease experienced by Aboriginal and Torres Strait Islander people (ABS 2013). Both internationally and cross-culturally peer-reviewed literature has established associations, explored pathways and biological mechanisms providing a critical knowledge base on the role of social factors on health (Braveman, Egerter & Williams 2011). Despite these understandings, there is limited evidence on effective intervention strategies that address how these social factors influence health outcomes within the population (Alegría et al. 2018; Bambra et al. 2010; Luchenski et al. 2018; Thornton et al. 2016).

Recent government consultations highlight the importance of self-determined and timely action on the social determinants of health for Aboriginal and Torres Strait Islander communities incorporating system responses that are coordinated, culturally relevant and strengths-based (Andermann 2016; Commonwealth of Australia 2017; Frier et al. 2020; Osborne, Baum & Brown 2013). Health systems face challenges in responding to the complex nature of the social determinants of health with collaborations required across health and social services, nonetheless the clinical frontline workforce have been recognised as a potential catalyst for change in any systems response (Andermann 2016). Clinical workforce approaches which include screening clients for social and emotional wellbeing (which include the social determinants of health) facilitate the early identification and management of needs, planned and coordinated responses and the monitoring of progress and outcomes (Langham et al. 2017).

In a current context, Aboriginal Community Controlled Health Services (ACCHOs) and primary health care services are 'doing whatever it takes' to meet the social and emotional wellbeing needs of Aboriginal and Torres Strait Islander people which includes addressing the social determinants of health in service delivery (CREATE 2020). Consultations with ACCHOs have highlighted key principles which inform holistic approaches to the social determinants of health including self-determination, accessible and culturally safe care and strong partnerships that support clients to navigate social services (CREATE 2020). A recent document analysis of 67 ACCHO annual reports found that all services were working to improve clients' intermediary social determinants of health, specifically material circumstances, biological, behavioural and psychosocial factors (Pearson et al. 2020). Whilst structured and funded Aboriginal and Torres Strait Islander health assessments for preventative care are widely implemented, these assessments are limited by a biomedical focus that inadequately addresses social and cultural factors (Bailie et al. 2019). Across organisations there are varied responses depending on the capacity (i.e. workforce, skills, training and resources) of the primary health care service (CREATE 2020; Andermann 2018). Furthermore, service delivery protocols for addressing the social determinants of health and more broadly data systems for monitoring their actions are not well established (Golembiewski et al. 2019; Osborne, Baum & Brown 2013).

Strengths-based, person centred and empowerment approaches are often used synonymously to describe the delivery of health care for Aboriginal and Torres Strait Islander people. These approaches promote individuals control over their own lives and focus on abilities and resources to enable self-determination (Bovill et al. 2019; Gibson et al. 2020; Saleebey 1996). Aboriginal and Torres Strait Islander people who have increased control and mastery over their lived experiences are empowered in their engagement with social and health services (Tsey et al. 2010). Health care services commonly describe intentions to deliver strengths-based approaches, yet the practical and genuine implementation with Aboriginal and Torres Strait Islander people is still emerging in practice (Askew et al. 2020; Gibson et al. 2020). Holistic case management models are well suited for strengths-based practice which focuses on empowering people to take charge of their own lives and to support the identification of existing strengths and resources (Saleebey 1996). Case management approaches whilst diverse across disciplines and in different contexts usually include the following core functions;

assessment, planning, linking, monitoring, advocacy and outreach services (Huber 2002). Case management approaches in primary health care with Aboriginal and Torres Strait Islander people report improvements in self-rated health status, reduction in depression and improved measures of diabetes control (Askew et al. 2015). These findings suggest that patient led case management has the potential to enhance holistic approaches to social and emotional wellbeing (Askew et al. 2015).

The effects of colonisation and the continuing social and political oppression and dispossession of Aboriginal and Torres Strait Islander communities has contributed to significant socio-economic and health inequities (Gracey & King 2009). Persistent and disproportionate inequalities experienced by Aboriginal and Torres Strait Islander people highlight the need to better understand and respond to social and emotional wellbeing needs which includes the social determinants of health. There is a pressing need for coordinated best practice responses to social and emotional wellbeing screening and management, dedicated resources, training and ongoing monitoring (Langham et al. 2017). Existing evidence has not yet described approaches that collectively inform health care responses for Aboriginal and Torres Strait Islander social and emotional wellbeing. To address this gap, a pilot program has been designed within a research setting and includes the following key elements: i) identifying unmet needs, ii) strengths-based case management, iii) document and monitoring, iv) culturally relevant supervision and v) evaluation. The aim of this manuscript is to describe and critically explore the programs key elements from an Aboriginal and Torres Strait Islander perspective as part of strengthening practice-based evidence on social and emotional wellbeing.

# 5.1.3 Discussion

# Program Context

The Cultural Pathways Program is implemented by Wardliparingga Aboriginal Health Equity (Wardliparingga) in the South Australian Health and Medical Research Institute (SAHMRI). Wardliparingga undertakes research that is of relevance to South Australian Aboriginal and Torres Strait Islander communities through partnerships, collaboration, respect, reciprocity and for the benefit of community (South Australian Health and Medical Research Institute 2014). The Cultural Pathways Program is designed and implemented by Aboriginal and Torres Strait Islander people as a response to community

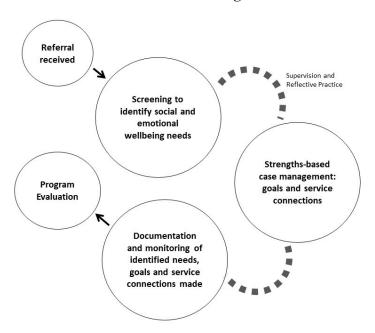
identified needs. The program is implemented within an Indigenous methodological framework and from inception to implementation the program has been underpinned by Aboriginal and Torres Strait Islander ways of knowing, being and doing (Martin-Mirraboopa 2003; Rigney 1999; Saunders, West & Usher 2010; Smith 2012; Wilson 2008). Priority areas for research were established through extensive consultation and engagement with the community (King & Brown 2015). All programs of work implemented by Wardliparingga have Aboriginal and Torres Strait Islander leadership and governance, through these structures the community consistently highlighted that more holistic responses, which included the social determinants of health, were required. The research team are predominantly Aboriginal and Torres Strait Islander researchers who bring wisdom and experience to the development of the program approach and implementation ensuring consistent alignment with Aboriginal and Torres Strait Islander ways of knowing, being and doing. The program described in this manuscript was approved by the Aboriginal Health Research Ethics Committee of South Australia [AHREC-04-17-733].

The program approach includes comprehensive screening utilising a specifically developed holistic screening tool to identify unmet social and emotional wellbeing needs. Following screening, facilitators implement strengths-based case management through goal setting, prioritisation and brokering connections to services. Program structures embed documentation and monitoring of the program's social and emotional wellbeing responses, actions taken to address needs and outcomes for participants. These elements are underpinned by culturally relevant supervision, reflective practice and evaluation. The program approach critically explores the benefits, cultural relevance and responsiveness of common practices in case management. Through a combined understanding of these approaches the program seeks to inform the evidence base for strengthened and coordinated responses to Aboriginal and Torres Strait Islander social and emotional wellbeing.

Program delivery is undertaken by male and female facilitators with workforce roles informed by a navigator approach, to assist individuals' engagement with the health care system and to overcome any barriers to care (Bernardes et al. 2018; Henderson & Kendall 2011; Whop et al. 2012). Referrals are received from a large-scale population-based biomedical cohort study of Aboriginal and Torres Strait Islander South Australians. As part of the study all participants receive a comprehensive health assessment that includes

questions regarding their social and emotional wellbeing. Further to this, community engagement and consultations highlighted that post-study follow up responses for participants would require addressing social and emotional wellbeing needs such as psychosocial health, financial literacy, food security and material circumstances. Participants are offered a referral to the Cultural Pathways Program, if unmet social and cultural needs are identified during the assessment. The implementation setting replicates real world service delivery models where presentation may initially be for a physical health need. Upon receipt of referrals from the study team, the Cultural Pathways Program facilitators connect with participants and implement the flexible participant led case management process (Figure 5.1).

Figure 5.1: Cultural Pathways Program elements for responding to Aboriginal and Torres Strait Islander social and emotional wellbeing



Program elements informing a social and emotional wellbeing response have been detailed within the following sections, providing the theoretical underpinnings, Cultural Pathways Program approach, embedded Aboriginal and Torres Strait Islander ways of working and opportunities for strengthening practice.

# Identifying unmet needs

Screening and assessment is a common first point of engagement in health settings and appropriate screening delivered as part of routine practice can enhance the timely and effective identification of needs and accordingly inform responses or prompt a more

comprehensive assessment (Andermann 2018). Indigenous specific health assessments are associated with improved preventive care for a range of health needs, however a greater focus is needed on social and cultural factors (Bailie et al. 2019). Cultural Pathways Program facilitators implement a modified Social Needs Screening Tool (Health Leads 2016) to identify unmet social needs of participants. Developed through an Aboriginal and Torres Strait Islander researcher led process, with community input to ensure cultural relevance and responsiveness, the adapted holistic tool covers wellbeing domains including mental health and cultural and community connection and social domains including financial and food security, transport, employment, housing, and social isolation. The process of cultural development ensures the questions are relevant, asked the right way, with cultural meaning and are best able to identify the unique needs of Aboriginal and Torres Strait Islander participants (Brown et al. 2013; Langham et al. 2017). Screening processes for the social determinants must be accompanied by plans for action (Davidson & McGinn 2019; Gottlieb, Fichtenberg & Adler 2016), and as part of the program's case management approach the screening process assists the Facilitator to understand participant needs and enables the identification and prioritisation of participant goals. By implementing a structured and consistent approach, identifying and documenting unmet needs enables the measurement of actions, activities and the monitoring of participant outcomes.

# Strengths-based case management

The program's case management approach includes goal setting, prioritisation and brokering connections to services. Facilitators work in partnership with participants and tailor responses to individual circumstances and needs. A strengths-based approach to case management ensures facilitators focus on clients' abilities, talents and resources to enable client's self-determination skills, develop resilience and the ability to respond or navigate similar situations in the future (Saleebey 1996). Goal setting is a common step in the case management process (Kisthardt, Gowdy & Rapp 1992) with theoretical concepts highlighting the importance of collaboration for effective goal setting (Vanpuymbrouck 2014). An individuals' sense of control and autonomy influences their willingness to set goals and efforts for achieving them (Vieira & Grantham 2011). The Australian Integrated Mental Health Initiative (AIMhi) is an existing framework which uses strengths-based story telling (Nagel & Thompson 2007). The Cultural Pathways

Program implements a goal and priority setting framework utilising the AIMhi Pictorial Care Plan (Menzies School of Health Research 2020) to explore physical, emotional, spiritual, cultural, family, social and work contexts to identify worries, strengths and resources. Consistent with Aboriginal and Torres Strait Islander ways of working, facilitators work in partnership with participants to identify and prioritise issues of most importance that will support improved wellbeing. As part of the strengths-based, empowerment and person-centred approaches, participants define their own priorities contributing to enhanced autonomy, control and self-efficacy.

As part of the 'brokering' approach to case management, facilitators connect participants with services to meet their needs. Making a referral to other services, organisations or agencies is widely implemented in health and social services. Social and emotional wellbeing and social determinants of health needs span across sectors with often multiple services and agencies involved, this requires coordination to minimise the burden on service users and to enable referrals and connections (Kowanko et al. 2009). Brokering connections relies on relationships, understandings of what is available across the breadth of health and social needs and understandings of culturally relevant services (McKenna et al. 2015; Treatment Center for Substance Abuse 2000). To support this approach, facilitators undertake service mapping exercises to identify the available services and will pro-actively seek the most appropriate service to connect a participant to and reduce barriers to access these services (Huber 2002). Facilitators actively support participants to access services by contacting services on behalf of participants, supporting participants when they contact services themselves and follow up contact with participants to monitor progress. If necessary, facilitators address any challenges or barriers to support the best possible outcome. The active and coordinated approach to brokering connections enhances service access for participants and enables the program to also monitor brokerage outcomes.

## Documentation and monitoring

Program monitoring involves measuring and reporting on progress and creates opportunities for continuous quality improvement (Hudson 2016). Currently, health services rarely systematically collect data about or measure activity on the social determinants of health and require a mechanism to monitor and evaluate the impact of social and emotional wellbeing services they provide to address health outcomes (Langham et al. 2017; Reeve, Humphreys & Wakerman 2015). Comprehensive

understandings of the most appropriate measures for Aboriginal and Torres Strait Islander social and emotional wellbeing and the social determinants of health are still emerging. Existing national measures of wellbeing include psychological distress, positive wellbeing, anger, life stressors, discrimination, cultural identification and removal from natural family (AIHW 2009). Measures for the social determinants of health as described by the World Health Organization (WHO) Conceptual Framework (Solar & Irwin 2010) and outlined in the Aboriginal and Torres Strait Islander Health Performance Framework (AHMAC 2017) include domains such as connection to Country, education, employment, health system, housing, income, and transport.

The Cultural Pathways Program combines social and emotional wellbeing and social determinants of health measures as part of the programs' monitoring framework. The program utilises REDCap (Research Electronic Data Capture), a secure web platform for managing online databases (Harris et al. 2009). The platform collects participant information, demographics, and activity data which includes when and how people are contacted and the services provided by social/health domain. The program measures factors such as unmet needs, identified goals, whether they have been achieved and the service connections made. The program utilises routine data for ongoing monitoring, quality improvement and as part of funding requirements and obligations. The data collected by the program was informed by Aboriginal and Torres Strait Islander understandings of health and wellbeing and the wisdom and expertise of the research team and community. The process included the collective development of culturally relevant measures in relation to social and emotional wellbeing, specifically practical ways to measure progress towards addressing complex social and cultural factors. This process enabled the program to capture information that is useful and relevant for Aboriginal and Torres Strait Islander people. A structured and consistent approach to identifying needs and a specifically designed monitoring framework enables the program to measure progress or outcomes which can be used to understand the needs of service users, to plan responses and to advocate for resources (Harfield et al. 2018).

# Culturally relevant supervision

Reflective practice and clinical supervision are recognised by many professions for their role in supporting enhanced clinical practice as well as the health and wellbeing of the workforce (Koivu, Saarinen & Hyrkas 2012; Scerra 2012; Thompson & Pascal 2012).

This is particularly important for Aboriginal and Torres Strait Islander health workers and practitioners who have complex experiences including burnout and vicarious trauma (Nelson et al. 2015). The Aboriginal and Torres Strait Islander health workforce, and non-Indigenous workers in Aboriginal and Torres Strait Islander health contexts require access to high quality cultural and clinical supervision which supports cultural safety, improved practice and wellbeing (Bainbridge, McCalman, et al. 2015; Truong, Paradies & Priest 2014). Available frameworks for culturally appropriate supervision with Aboriginal and Torres Strait Islander people include considerations for working with community, looking after self, understanding of roles and professional practice (Koivu, Saarinen & Hyrkas 2012; Nelson et al. 2015; Scerra 2012; Victorian Aboriginal Child Care Agency (VACCA) 2013; Victorian Dual Diagnosis Education and Training Unit (VDDI) 2012). Despite the important role of culturally relevant clinical supervision in enhanced service delivery and the support and retention of the workforce in health care settings (AHCSA 2020), evidence based understanding of applied practice models are still emerging in peer reviewed evidence.

The Cultural Pathways Program utilises these existing frameworks as well as the knowledge and experience of program staff to implement a culturally relevant reflective practice and supervision model. An experienced Aboriginal clinician supports facilitators through a range of structures including weekly clinical yarning, one to one yarning and debriefing opportunities as required. Facilitators share perspectives, feelings, challenges, barriers and enablers in relation to both clinical practice as well as system, policy and organisational factors which impact the participant, Facilitator, or the program. Fundamentally the supervision and reflective practice model is culturally grounded in relationships and yarning to support the cultural safety for Aboriginal and Torres Strait Islander participants whilst also enabling the retention and wellbeing of the Aboriginal and Torres Strait Islander workforce.

# Developmental Evaluation

Evaluating health programs and initiatives supports implementation across different contexts utilising insights into how and why they work and whether they have been effective (Lokuge et al. 2017). There is an increasing recognition of the important role of evidence-based programs featuring high quality and culturally relevant evaluation (Productivity Commission 2019). The Cultural Pathways Program is underpinned by an

Indigenous methodological evaluation framework which utilises developmental evaluation, an approach to evaluation that supports innovation and adaptation in complex environments (Fagen et al. 2011; Patton 2010), and is consistent with Indigenous methodology and participatory approaches requiring partnerships, trust and shared decision making (Gamble 2008). The key to developmental evaluation is that the evaluator works with the team in real-time, asking evaluation questions, examining and tracking implications of adaptations and providing timely feedback as the program is implemented and modified or adapted as needed. The evaluator as an Aboriginal woman is immersed in as an insider drawing heavily on reflective practice and utilising the cultural knowledge and expertise of the evaluator as part of the evaluation method. The aim of the evaluation is to understand the process including what was delivered, how it was implemented and the experiences of program participants. The evaluation through reflective and formative methods supports further understanding on the interactions between facilitators, program participants and the broader health and social service contexts. The evaluation framework includes community engagement, governance and approaches which have been purposely selected for their consistency with Indigenous methodologies. This framework ensures that the participation and voice of the community are therefore embedded throughout implementation supporting has tangible benefits to the community (South Australian Health and Medical Research Institute 2014).

# 5.1.4 Conclusions

There is a knowledge to action gap on how to assess and address the social determinants of health within clinical practice to inform the development of coordinated, culturally relevant and strength-based responses to meet the holistic social and emotional wellbeing needs of Aboriginal and Torres Strait Islander people and communities.

Primary health care services, often as the entry point for accessing health services, are well positioned to implement coordinated health equity responses which include addressing the social determinants of health (Pereira, Salvi & Verloo 2017; Rasanathan et al. 2011). The absence of a readily applied model creates challenges for the provision of coordinated, resourced and systemic responses to the social determinants of health (CREATE 2020). Routine screening for unmet needs, implementing strengths-based practice, connecting people to what they need, monitoring service provision and providing clinical and cultural support for the Aboriginal and Torres Strait Islander workforce align to existing practice and are transferable across contexts. Continuous quality improvement and monitoring enables primary health care services to embed new practices into services, systems and routines (Gardner et al. 2010).

The ability to implement holistic approaches to Aboriginal and Torres Strait Islander health through the intersection of health and social services requires adequate resources, training and support to clinical workforce (Andermann 2016), including consideration of roles, responsibilities, scope of practice and readiness to implement strengths-based approaches. These changes cannot be implemented without addressing the ongoing impacts of racism and oppression of Aboriginal and Torres Strait Islander people, allowing for culturally safe systems which are able to meet holistic social and emotional wellbeing needs (Curtis et al. 2019; Durey 2010; Laverty, McDermott & Calma 2017; Muise 2019; Secombe et al. 2019).

The Cultural Pathways Program builds on existing approaches to contribute to practice-based evidence of culturally relevant case management approaches which can be utilised as part of routine care to strengthen the systematic identification and response in primary health care delivery. The combined understandings of the elements outlined in this manuscript provide a framework to inform service planning and tailored implementation which can strengthen social and emotional wellbeing responses for Aboriginal and Torres Strait Islander people.

#### **About the contributors**

Consistent with cultural protocol we position the contributors to this manuscript:

Tina Brodie is an Aboriginal woman with connections to Yawarrawarrka and Yandruwandha. She is a third year PhD Candidate at The University of Adelaide in the Faculty of Health and Medical Sciences and a Clinical Research Associate in Wardliparingga Aboriginal Health Equity, South Australian Health and Medical Institute. Her Research is exploring Aboriginal and Torres Strait Islander Social and Emotional Well-being, specifically the social determinants of health. Tina has over ten years of experience in Aboriginal and Torres Strait Islander Health in multiple clinical, project and leadership roles working with Aboriginal and Torres Strait Islander children and families. Tina has expertise in Indigenous methodologies and culturally responsive and ethical ways of working and engaging Aboriginal and Torres Strait Islander people and communities in research.

Odette Pearson is a Kuku Yalanji/Torres Strait Islander Population Health Platform Lead in Wardliparingga Aboriginal Research Unit at South Australian Health & Medical Research Institute. Her experience and post-doctoral training in Aboriginal health policy, health systems and inequity comprises a unique comprehensive skillset relevant to existing and emerging complexities of Aboriginal health and well-being. Specifically, Odette seeks to understand how institutional policies and practices drive health and social inequities experienced by Indigenous populations. Her novel approach is the use of community-level information to show and explore the reasons for variations in disadvantage both within the Aboriginal community and between the Aboriginal and non-Aboriginal community. Integral to her research is the inclusion of Aboriginal communities in defining their health and well-being and how Indigenous data can be governed in the future to derive greater benefit for the population.

Luke Cantley has family connections to the Gunditjmara nation of Victoria and is a Research Associate located within Flinders University. Through his research, Luke is determined to solidify Aboriginal culture as a protective factor within the child protection system, whilst exploring the nuances between child safety and cultural safety. Luke holds extensive knowledge on the role unmet social and cultural needs have on positive health outcomes within the Aboriginal and Torres Strait Islander community and holds a strong passion for advocating for increased health care utilisation for health care consumers.

Luke has gained extensive experience working as an Aboriginal Health Worker within a strengths-based approach across diverse sectors including Prison health, Primary Health Care, Public Housing and Mental Health Services. Developing expertise in 1) Culturally appropriate and ethical ways of engaging within the community, 2) Health and Wellbeing assessment methods fostering participatory action research, and 3) Social inequities generated by reduced access to services or resources.

Peita Cooper has a Bachelor of Social Work and currently works within the justice sector. Peita commenced as a Graduate in Wardliparingga Aboriginal Health Equity Theme, at the South Australian Health and Medical Research Institute (SAHMRI). As a Program Facilitator, Peita contributed to the delivery of strengths-based case management and developing culturally responsive practice with Aboriginal and Torres Strait Islander peoples' and communities. Her previous experience includes working in the disability sector.

Seth Westhead has family connections to the Awabakal and Wiradjuri nations of NSW and is a Research Associate with Wardliparingga Aboriginal Health Equity Theme, South Australian Health & Medical Research Institute. Through his research work, Seth strives to better understand how social and cultural determinants drive health and social inequities within society, particularly as it relates to the Indigenous population. He seeks to better equip communities and young people with tools and evidence for public health advocacy and enable communities to translate health research into meaningful action. Specifically, Seth has expertise in the: 1) conceptual development of Aboriginal specific social determinants and well-being frameworks and tools, 2) implementation of projects involving community engagement and community-led governance structures 2), and 3) undertaking of qualitative research methodologies and community and stakeholder participation interpretation of findings.

Alex Brown is an Aboriginal medical doctor and researcher, he is the Theme Leader of Wardliparingga Aboriginal Health Equity and Professor of Medicine at the University of Adelaide. He grew up on the south coast of New South Wales (NSW) with family connections to Nowra, Wreck Bay and Wallaga Lake on the far south coast of NSW. Over the last 20 years, Alex has established an extensive and unique research program focused on chronic disease in vulnerable communities, with a particular focus on outlining and overcoming health disparities. He leads projects encompassing epidemiology,

psychosocial determinants of chronic disease, mixed methods health services research in Aboriginal primary care and hospital settings, and randomised controlled trials of pharmacological and non-pharmacological chronic disease interventions. Alex has been heavily involved in engaging government and lead agencies in setting the agenda in Aboriginal cardiovascular disease management and control and chronic disease policy more broadly. He sits on a range of national committees, and co-chairs the Indigenous Research Health Fund through the MRFF.

*Natasha Howard* is the Wardliparingga Platform Lead: Implementation Science. The platform incorporates a systems view and privileges Indigenous knowledge to deliver mixed-method inter-disciplinary perspectives which aim to generate policy and practice-based evidence on the social determinants of health. Her experience spans both the health and social sciences, applying population approaches to investigate how the social and built environment enables and promotes cardiometabolic health and well-being, notably for priority populations. She has been active in advocacy and mentoring of the local population health community in both research and practice.

## **Funding**

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# Acknowledgements

This work was supported by the Wyatt Benevolent Institution Inc.

# **Conflict(s) of Interest**

None

# **Ethical Approval**

This program was approved by the Aboriginal Health Research Ethics Committee of South Australia (AHREC 04-17-733).

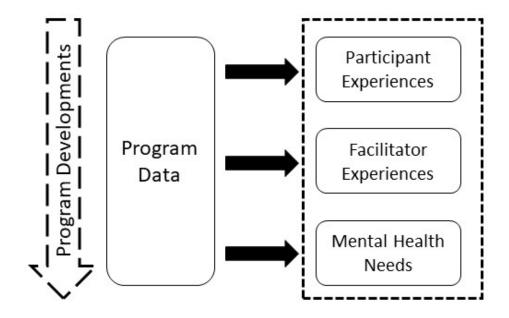
# 5.2 PROGRAM EVALUATION OF IMPLEMENTATION PROCESSES AND EXPERIENCES

### 5.2.1 Introduction

Section 5.2 is structured based on the program elements and evaluation method detailed in 5.1. Aligning with Indigenous methodological approaches, developmental evaluation and the evaluation framework were selected for consistency, suitability and adaptability with an Indigenous methodology. A developmental evaluation enables alignment with the practices of Wardliparingga and is consistent with participatory approaches which in this study included partnerships and shared decision making (Gamble 2008; South Australian Health and Medical Research Institute 2014). Taking action on the social determinants of health in practice is complex across multiple systems, services and disciplines in a variety of contexts and between participants, facilitators and stakeholders (Bambra et al. 2010). Developmental evaluation supports understanding complex systems utilising a range of evaluation methods to suit purpose and to innovate, reflect and adapt in response to these complex systems (Bailie et al. 2020; Fagen et al. 2011; Patton 2010).

As part of the developmental evaluation specific evaluation methods were selected to suit the purpose and ensure holistic mixed-methods understandings of the programs' development, and implementation. The process of implementation of method to reporting of results was iterative and preliminary findings, along with participatory approaches, informed further analysis. Program data were utilised through reflective practice for ongoing quality improvement and this reflective process informed the selection of evaluation components. The evaluation components include 1) Program Data; 2) Program Developments; 3) Participant Yarns; 4) Mental Health Needs; 5) Facilitator Yarns. The inter-related, iterative, reflective and mixed methods interactions between these components are displayed in Figure 5.2.1.

Figure 5.2.1: Cultural Pathways Program Evaluation Components



# 5.2.2 Methods

The components for the evaluation and associated methods are summarised in Table 5.2.1.

Table 5.2.1: Summary of Program Evaluation components, associated methods and data sources

|                         | Method of  | Participants   | Data Source  |
|-------------------------|--|--|--|
|                         | Collection   |  |  |
| Program Data            | Data collected by Facilitators as part of program implementation | Cultural Pathways Program Participants who consented to the evaluation and had first visit documentation completed.  | Program Data Including: -Participant Information -First Screening Tool -Goals and Priorities -Progress Notes |
| Program<br>Developments | Reflective Practice  | Evaluator and<br>Program<br>Facilitators   | Recorded Reflections and Observations  |
| Participant Yarns       | Semi-structured<br>qualitative<br>interviews                     | Random sample of 5 female and 5 male program participants who consented to the evaluation and had first visit documentation completed and reside in the metropolitan Adelaide region.                | Transcribed interviews with participants   |
| Mental Health<br>Needs  | SOAP Note<br>Qualitative Content<br>Analysis                     | Cultural Pathways Program Participants who consented to the evaluation, had first visit documentation completed and screened yes for "feeling no good in myself or my spirit" on the Screening Tool. | Program data recorded in case notes.   |
| Facilitator Yarn        | Workshop<br>Discussion   | Program<br>Facilitators  | Recorded notes from workshop discussion.   |

# Program Data

As outlined in 5.1 'Documentation and Monitoring', participant information, demographics, and activity data were collected as part of the delivery of the program. The

program data outlined in Table 5.2.2 are used to describe the implementation of the program and the interactions between Facilitators and participants. This was explored through a secondary analysis of data collected as part of the delivery of the program.

Primary sources of written data collected by Facilitators included:

ISBAR Documentation is completed after the first face to face contact has been held with a new participant. An ISBAR entry is used as a clinical handover tool and more specifically for the program, provides an introduction of the new participant including:

Identify: Document what type of contact occurred, where the event took place, who was present. In the Identify section, document any conversations held regarding program expectations. Provide a summary of the Participant, age, location, cultural status, observation from first session.

Situation: Document the reason for the session

**B**ackground: Document any relevant history e.g. previous episodes with the program. Anything the Participant discloses during first session, potential risks, episodes of care (hospitalisation, imprisonment), major events.

Assessment: Document any areas the Participant identifies as priority or needs. Any assessment of Participant carried out by the Facilitator.

Recommendation: Document any actions required to be carried out by either the Facilitator or Participant

A SOAP note entry documents progression, and is required after any interaction with, or for, the participant and is collected as part of the service provided to participants including dates, times and types of contacts, goals identified by participants and any service connections made. Facilitators use SOAP notes to record reflections of the engagement or interaction.

The documentation text of SOAP notes describe:

- The type of contact, location, people present, etc.
- Any changes of the issue/s from the last session from the participants perspective.
- Observations of the participant's behaviour during the session.

- An assessment of progress towards participants self-identified priority areas and the objectives established in the previous session including any objectives that have been met since the previous session.
- Assessment of any themes or patterns within the session and should inform the next steps or 'plans' for future sessions.
- Plans for follow up action including the steps to be taken after the session has ended including any relevant activities or tasks that will need to be made on the part of the Facilitator or participant.

### **Participants**

Cultural Pathways Program participants were included if they had consented to participate in the research and had completed the first screening tool and ISBAR documentation after the first meeting. Participants could decline to participate in the research and still receive support from the Cultural Pathways Program. There were no exclusion criteria.

#### Data Source

Data sourced from Cultural Pathways Program REDCap database, as described in Table 5.2.2 and the comprehensive data dictionary attached in Appendix 5.2 included: Participant information, First screening tool, ISBAR documentation, Priority and Goal Setting and Progress Notes (SOAP).

Table 5.2.2: Summary of Cultural Pathways Program Data

| <b>Data Collection Domain</b> | Variable  |  |
|-------------------------------|---|--|
| Participant Information       | Date of referral Referral source Self-identified Gender Community/Town Postcode Landscape Language Group  |  |
| ISBAR                         | Date of session Written Documentation   |  |
| Screening Tool Domains        | Food Security Material Circumstances Health Care Access Transport Housing Employment /Education Literacy Health Care Psychosocial Family Community Connection Safety Behavioural Culture Other Concerns |  |
| Goals                         | Goal # Domain Date Established Status Date Completed  |  |
| Progress Notes (SOAP)         | Date of session Time session started Time session ended Documentation Contact type Contact mode Service contact mode P/c outcome Attended session Indicator Met Indicator Domain                        |  |

# Analysis

A descriptive analysis of program indicators was undertaken to explore participant engagement and brokerage to social and health services. Frequencies for selected variables were utilised to describe the program context, participant characteristics, unmet needs and the strengths-based case management model. Analyses were undertaken within

IBM SPSS Statistics for Windows, Version 27 (IBM Corp. 2010). Frequencies were exported into Microsoft Excel for Windows 365 (Microsoft Corporation 2022a) for the creation of results tables.

### Program Developments

Program developments included innovations, adaptations or changes made throughout the implementation of the program. Reflective approaches were utilised to implement changes, monitor implications and make further refinements.

### **Participants**

Consistent with the Indigenous methodology, Aboriginal and Torres Strait Islander knowledges and lived experience underpinned developmental evaluation approaches which enabled the embedding of cultural knowledge and use of the skills, strengths, knowledge and expertise of the evaluator as an Aboriginal woman. As part of the developmental evaluation the Evaluator worked with the team in real-time, asking evaluation questions. Reflective approaches were embedded through the yarning supervision model with Facilitators, throughout the implementation and delivery of the program.

### Data Source

Data sources included written documentation of reflections or observations recorded during reflective practice from the perspective of the evaluator. These sessions were delivered through a range of structures including weekly clinical yarning, one to one yarning and debriefing opportunities as required. Facilitators were invited to share perspectives, feelings, challenges, barriers and enablers in relation to both clinical practice as well as system, policy and organisational factors which impacted the participant, Facilitator, or the program.

Reflective Practice explored the themes and constructs detailed in Table 5.2.3.

*Table 5.2.3: Reflective Practice Themes and Constructs* 

|  | Themes and Constructs   |
|--|---|
| Participant                                | <ul> <li>Participant response to strength-based approach and tools</li> </ul>   |
|  | What seems to work well or what doesn't   |
|  | Reflections of participant change process   |
| Practice                                   | <ul> <li>Facilitator experience of delivering intervention and tools</li> </ul>   |
|  | Delivery modes/ methods/approaches  |
|  | Record keeping/data collection  |
| Stakeholder/services                       | Responsiveness  |
|  | Cultural appropriateness  |
|  | • Flexibility   |
|  | Referral processes (waitlists, eligibility)   |
| Context, System, Policy,<br>Organisational | <ul> <li>Funding Provider (KPIs, requirements, expectations)</li> <li>Broader social issues impacting the participant/<br/>delivery of intervention (racism, housing, cost of<br/>electricity, cost of living, and services not available)</li> </ul> |

# Analysis

As part of the iterative study design reflections informed other evaluation methods, approaches and analysis. A review of documented program implementation reflections and observations were thematically mapped against the program elements to identify patterns and themes (Braun & Clarke 2006; Graneheim & Lundman 2004).

### Participant Yarns

Semi-structured qualitative interviews utilising a yarning approach were undertaken with participants to understand experiences of participants in the program. Yarning is an Aboriginal and Torres Strait Islander approach to communication which is based on deep listening and conversation (Bessarab & Ng'Andu 2010; Geia, Hayes & Usher 2013; Walker et al. 2014).

### **Participants**

Yarning interview participants included Cultural Pathways Program participants living in metropolitan Adelaide, South Australia, who had consented to participate in the research component of the Cultural Pathways Program, and who had completed the first screening tool and ISBAR documentation.

### Sample and Recruitment

To achieve a sample which represented Cultural Pathways Program Participants, a random sample was generated using de-identified participant identification numbers (Marshall 1996). These were then extracted from the program REDCap database (Harris et al. 2009) into an excel spreadsheet (Microsoft Corporation 2022a) and assigned a random number. The evaluator proceeded to contact participants by telephone as per recruitment guide (Appendix 5.4). The recruitment process was flexible with a face-to-face yarn scheduled at a time and location most convenient for the participant.

The sample size included 10 participants (5 female participants and 5 male participants). Participants were assigned a subgroup utilising program activity data, that included program indicators drawn from individual case notes to ensure the inclusion of participants with varied engagement with the program. These three subgroups were defined as 'Indicators Met', 'Partially Met' and 'No Indicators Met'. Program indicators were recorded as 'met' when an activity had been undertaken or outcome achieved to meet a participant need (e.g., connected to financial counselling, supported to access mental health support etc).

This approach aimed to avoid bias towards the potential inclusion of participants who had positive experiences or engaged more intensively with the program. The program indicators as described above were used only for inclusivity of the sample to ensure experiences of participants with varied levels of engagement with the program were captured. These subgroups were defined with input from the Advisory Group. Participant contact details were provided to Evaluator (TB), to contact female participants, explain the purpose of the evaluation and invite participation in a semi-structured yarning style interview at a time and location convenient to them.

The evaluator as an Aboriginal woman developed a culturally appropriate strategy for interviewing male participants in consultation with senior male Researcher (AB) and conversations with other Aboriginal and Torres Strait Islander male researchers on the most appropriate approach. Male participants were contacted initially by a male Research Assistant (RA) to confirm attendance at the interview and confirm attendance of both the female researcher and male RA at the interview.

The nature of the program evaluation required the interviewer to have extensive content and context knowledge of the program and its delivery to get the most out of the interviews and therefore the decision was made to conduct the interviews together. If participants were not comfortable with the female researcher in attendance the male RA would conduct the interviews alone. The recruitment script and interview guide developed to support the Aboriginal male RA are attached (Appendix 5.4).

The interview time was dependent upon on the participant and allowed for up to three 30-90 minute visits to facilitate connections to services or additional support after the interview. Wellbeing, safety and autonomy of participants were planned for as much as possible. This included implementing a relational and flexible approach, being guided by the participant, utilising a range of relationship building skills, and creating cultural safety and comfort for participants to freely express their experiences with the program (Bessarab & Ng'Andu 2010).

### Data collection

Yarning style interviews were conducted by the evaluator, an Aboriginal researcher (TB), with open ended questions relating to program implementation (Table 5.2.4). The interview process included describing the objectives of the study, gaining informed consent and building rapport with the participant as per the interview guide (Appendix 5.4). In addition to yarning about participant experiences, interviews were therapeutic and if any unmet needs were identified throughout the yarn these would be addressed by TB either at the end of, or as a follow up to the interview. Interviews were digitally recorded and transcribed with consent from participants, with all participants provided with the opportunity to review and edit their written transcript. Upon completion of the interview the researcher immediately recorded field notes and reflections (Charmaz 2014; Ortlipp 2008). In this instance, reflections from interviews were used to improve interviewer

technique and to monitor for considerations which could enhance future interviews (Charmaz 2014; Ortlipp 2008).

### Interview Questions

Questions were iteratively developed by reviewing the program protocol, aims and objectives and any themes highlighted throughout the implementation of the program. The questions were developed in consultation with the Cultural Pathways Program facilitators, research team and Advisory Group. The questions guided the interview as per the interview guide (Appendix 5.4). The yarning style naturally covered key questions and points throughout the semi-structured interview and therefore questions did not follow a linear order and themes were picked up at suitable times throughout the yarn.

Table 5.2.4: Semi-Structured Interview Questions

| Theme area                               | Question   |
|--|--|
| Addressing social and cultural needs     | Can you tell me more about what was happening for you at that time you first met the program? If you were to describe this program to a family member, what would you say? Would you refer someone else in your family or community to this program? If yes, why? If no, why?  |
| Interactions with<br>Program Facilitator | What did you think of the role of the Facilitator? What were the benefits you experienced from seeing the Facilitator?   |
| Strength-based practice                  | How did the program make you feel? Did working with the Facilitator make you feel more or less supported? In what ways? Did working with the Facilitator make you feel more capable? In what ways? Did working with the Facilitator help you to see or find any strengths you didn't know you previously had?  |
| Impact (Change)                          | What changes have you noticed since being involved in the program in yourself, or your day to day life? Can you describe any differences in your ability to manage the challenges you face day to day, compared to before? If you had to, would you be able to do the same thing that you did with the facilitator, by yourself? Have you since had any experiences where you have had to seek out and engage services? How has that gone for you? |

### Analysis

Analysis was an iterative process where reflective field notes were used and initial coding occurred to monitor the yarning interview approach and to monitor data saturation (Marshall et al. 2013; Marshall 1996). Data saturation was achieved at the point at which no new categories, themes or explanations were emerging. As part of the reflective approach the evaluator observed consistencies in participant experiences which indicated

that continuing was not necessary, and an adequate reflection of participant experiences had been achieved.

Recorded interviews were transcribed in Microsoft Word (Microsoft Corporation 2022b) and transcripts were imported into NVivo 12 software (QSR International Pty Ltd. 2020), designed specifically for analysing qualitative data. Content analysis method as described by Graneheim and Lundman (2004) was used to code transcripts and assign a label that reflected the meaning unit, or the words and/or statements with a similar underlying or central meaning, which aligned with the context of program delivery for Aboriginal and Torres Strait Islander communities. These codes were then allocated to categories aligning with the interview questions, including; cultural needs, relationship with the facilitator, strengths-based practice and the impact or change for the participant. In the instance of an emergent code that did not align to any of those categories, new categories were created. The categories were then grouped into higher level themes including a) participant experiences with the program; and b) the broader context, including the aims and objectives of the program to address social emotional wellbeing and the social determinants of health. The themes of strengths-based practice and impact/change were combined as part of the analysis due to the overlap between these constructs. For example, people were describing impact or change within themselves as part of the strengths-based program delivery approaches. A new category was created to reflect the 'program delivery'. A category was also created to reflect system and service barriers which were highlighted during the yarning interviews, and alignment with the overall objectives of the program and developmental evaluation.

### Mental Health Needs

As part of the iterative study design, mental health emerged as one of the highest unmet needs of participants and a topic of many reflective practice conversations throughout program implementation. There was a need to better understand mental health needs of participants and as such a small sub-study was undertaken to understand the following questions:

- 1. What were the specific unmet need of participants in relation to psychosocial status?
- 2. What was the response of the program and the outcome for participants?

# 3. What were the barriers and enablers to access as recorded in the notes by Facilitators?

### **Participants**

Cultural Pathways Program participants who a) consented to the research process b) received the screening tool and identified psycho-social domain (screened yes to "feeling no good in myself or my spirit") as an unmet need and c) had ISBAR documentation completed.

### Data Source

ISBAR and SOAP notes by either phone or in person and with participants and does not include notes completed for contact with service providers on behalf of participants as the intention was to understand the participants perspectives and experiences regarding mental health.

### Data Extraction Tool

An extraction tool was developed (Table 5.2.5) to capture the following themes:

- The type of unmet psychosocial need the participant presented with,
- The type of response implemented by the Facilitators/Program, and
- Whether it was successful or not successful.

The extraction tool was trialled for 10 participants and then discussed with Senior Research Fellow before refining. Extraction of data occurred from the SOAP notes for each participant.

Table 5.2.5: Mental Health Needs Extraction Tool

| Domain                                 | Expression  |
|--|---|
| Psycho-Social Needs<br>Discussed       | Yes/No  |
| ISBAR Summary                          | [Text]  |
| Mental Health Need                     | Anxiety Depression Anxiety and Depression Other Not Documented  |
| Connection Brokered                    | Referral to GP Supported to access Mental Health Plan Counselling Community Program Information Provided None N/A |
| Service                                | [Text]  |
| Pt/F Led                               | Participant<br>Facilitator<br>Side-by-side<br>N/A   |
| Engagement in Mental<br>Health Support | Yes No Not documented N/A Unknown (Lost Contact)  |
| Summary                                | [Text]  |

### Analysis

IBM SPSS Statistics for Windows, Version 27 (IBM Corp. 2010) was utilised to identify eligible participants and export from SPSS to Microsoft Excel (Microsoft Corporation 2022a) with extraction as per the extraction tool. Excel software was used to create tables and frequencies for extracted variables. To identify barriers and enablers Cultural Pathways Program ID numbers were generated from SPSS and participants SOAP notes were then extracted from excel into text format for each participant and imported into NVivo 12 (QSR International Pty Ltd. 2020) by participant ID. Open coding of SOAP notes was undertaken for two participants to develop coding framework to answer the research question and subsequent coding undertaken to identify barriers and enablers which were grouped into categories.

### Facilitator Yarns

To understand the perspectives of the Facilitators a workshop explored a) program implementation/delivery, b) relationships with stakeholders and services and c) any system or context reflections. As a pilot program there were two Facilitators, and this method was selected accordingly to maintain confidentiality and anonymity whilst also ensuring their perspectives were captured as part of the evaluation.

### **Participants**

Male and Female Program Facilitators and the Evaluator.

#### Data Collection

Data included recorded notes from Facilitator Workshop. Workshop discussion topics were informed by the Reflections documented as part of the yarning supervision model and the iterative approach to support emergent understandings from program descriptive, qualitative interviews with participants and mental health SOAP note content analysis.

The topics were a guide for the yarn with Facilitators which was digitally recorded.

Table 5.2.6: Summary of Themes Discussion Topics

| Theme              | Discussion Point  |
|--------------------|---|
| Program Delivery - | Your thoughts on how participants felt about the screening tool.            |
| Participants       | How did they feel about the follow up phone calls?                          |
|                    | The brokerage model?  |
|                    | Is there anything you would change or do differently looking back?          |
|                    | How did you feel having challenging conversations? What did help?           |
|                    | What else could have helped to support you in these hard                    |
|                    | conversations? Were there any instances where you felt it was               |
|                    | inappropriate to talk about a participant's situation? e.g. in the analysis |
|                    | I noticed we often screened them as feeling no good in themselves or        |
|                    | their spirit but doesn't always appear that we discussed it again or        |
|                    | asked further about it.   |
|                    | How did you feel when "shit goes down" – when there was a crisis or         |
|                    | stressful event? What did help? What would have helped?                     |
|                    |   |

| Program Delivery -                 | What do you think about the support provided to Facilitators (e.g. the   |
|------------------------------------|--|
| Facilitator Support                | yarning model and approach)?   |
|                                    | What support didn't you have but wish you did?   |
|                                    | How would you make facilitator support better if this program was  |
|                                    | embedded in a primary health care service or social service?   |
|                                    |  |
| Program Delivery -                 | Looking back now is there anything about documentation and record  |
| Documentation and                  | keeping approaches/processes you would change? Why/Why not? e.g  |
| Recording                          | More tick boxes and less free writing?   |
|                                    |  |
| Program Delivery -                 | With the Participant led approach did we leave too much room? What   |
| Other                              | do you think an approach would look like that was able to do more  |
|                                    | therapeutic work around things like mental health?   |
|                                    |  |
| Service/Stakeholder                | How did you find making referrals? What made them successful? What   |
| Discussion Topics                  | were the challenges?   |
|                                    | How did you feel developing stakeholder relationships? Did you feel  |
|                                    | confident to establish relationships with services you were making   |
|                                    | referrals to? What got in the way?   |
|                                    |  |
|                                    | What do you think would improve being able to make relationships with  |
|                                    | What do you think would improve being able to make relationships with services/stakeholders?   |
|                                    |  |
| System / Context                   |  |
| System / Context Discussion Topics | services/stakeholders?   |
| •                                  | services/stakeholders?  Do you have any thoughts / reflections you want to share about the   |
|                                    | services/stakeholders?  Do you have any thoughts / reflections you want to share about the broader system/context that influenced your work? Social / system |

# Analysis

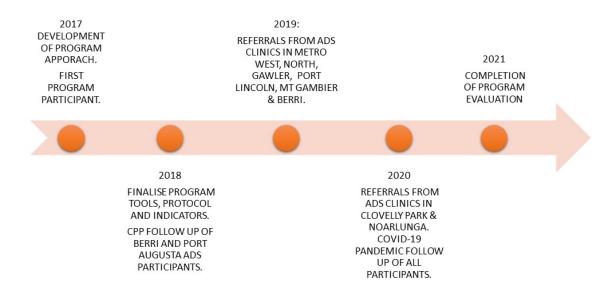
Analysis included a narrative summary (Savin-Baden & Niekerk 2007) of the key findings and perspectives of Facilitators, with key themes and discussion points purposively selected for alignment with the programs emergent findings as part of the iterative study design.

### 5.2.3 Results

### Program Implementation

The program was implemented throughout 2017-2021 as summarised in Figure 5.2.2. The stages progressed through program development, to piloting tools with a small number of participants, finalising program tools, protocol and indicators, and then accepting referrals from the Aboriginal Diabetes Study to implement the program approach with participants.

Figure 5.2.2 Cultural Pathways Program Implementation Timeline



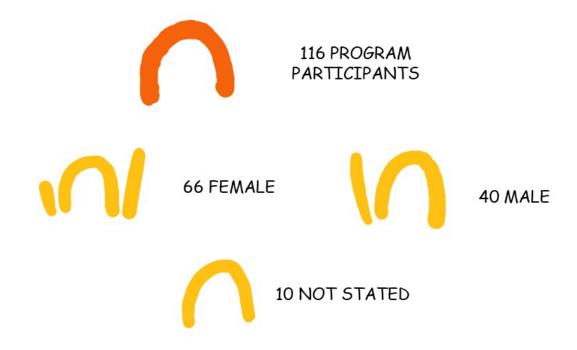
### Program Participants

The program received 350 referrals, with 95.7% (n=335) of those received from the Aboriginal Diabetes Study, 3.7% (n=13) were self-referrals and 0.6% (n=2) were family/community referrals.

Of the 350 referrals received, 116 participants had consented to participate in the research component of the program, had completed the first screening tool and had ISBAR documentation completed after the first meeting.

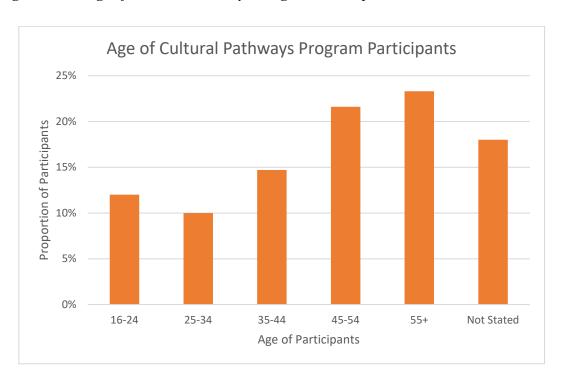
Participants self-identified gender upon entry into the program including; 56.9% (n=66) of participants who identified as female, 34.5% (n=40) as male and 8.6% (n=10) were not stated.

Figure 5.2.3: Self-identified gender of Cultural Pathways Program Participants



The age range of participants was 16-55+ years. Proportion of participants across age categories varied with 12% up to 24 years, 19% aged 25-34 years, 15% aged 35-44 years, and 45% aged 45+ years.

Figure 5.2.4: Age of Cultural Pathways Program Participants



In South Australia, a community project has adopted place-based approaches. The South Australian (SA) Aboriginal Landscapes Project (Landscapes) includes 19 geographical units in South Australia (Pearson et al. 2019). The Landscapes of participants were varied across South Australia however were primarily either regional or metropolitan with 37.1% of participants from Metro North/North East in Adelaide.

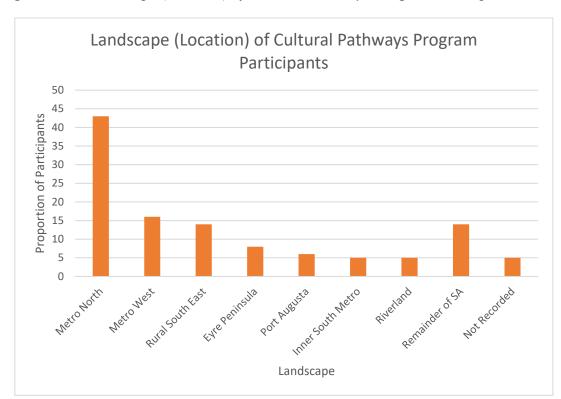


Figure 5.2.5: Landscape (Location) of Cultural Pathways Program Participants

# Screening for unmet needs

Facilitators undertook screening with 116 participants to identify unmet social and cultural needs. Participants identified an average of 8.4 unmet needs out of a total of 14. Overall, 77.1% (n=84) participants identified feeling unhappy or no good in themselves or spirit and 67.0% (n=73) participants wish they had more opportunity to learn and share culture.

Table 5.2.7: Unmet Social and Cultural Needs

| Domain and Screening Question  | Yes |      | No |      |
|--|-----|------|----|------|
|  | n   | %    | n  | %    |
| 1. Food Security: In the last 12 months have you   | 57  | 53.3 | 50 | 46.7 |
| ever worried about feeding yourself or your family?  |     |      |    |      |
| 2. Material Circumstances: In the last 12 months, have you received a bill and been worried about  | 51  | 47.2 | 57 | 52.8 |
| how you are going to pay it?   |     |      |    |      |
| 3. Health Care Access: In the last 12 months, have   | 49  | 45.8 | 58 | 54.2 |
| you needed to see a doctor or health professional  |     |      |    |      |
| but couldn't?  | 0.5 | 00.4 | 70 | 07.0 |
| 4. Transport: In the last 12 months, have you been unable to make an appointment or get where you  | 35  | 32.4 | 73 | 67.6 |
| need to go because you didn't have any transport?  |     |      |    |      |
| 5. Housing: Do you have stable and adequate housing at the moment?   | 86  | 81.9 | 19 | 18.1 |
| 6. Employment and Education: In the last 12  | 61  | 56.5 | 47 | 43.5 |
| months, have you been worried about work or  |     |      |    |      |
| study?   |     |      |    |      |
| 7. Literacy and Numeracy: Do you ever need help  | 24  | 22.4 | 83 | 77.6 |
| reading or understanding documents or forms (e.g. Centrelink, Medical forms, School forms)?  |     |      |    |      |
| 8. Health: Is there something about your health that   | 59  | 54.6 | 49 | 45.4 |
| is worrying you that you have not got help for?  |     |      |    |      |
| 9. Psychosocial: Have you been feeling unhappy or no good in yourself or spirit?   | 84  | 77.1 | 25 | 22.9 |
| 10. Family and Relationships: Do you have any big  | 59  | 56.7 | 45 | 43.3 |
| family issues or concerns?   |     |      |    |      |
| 11. Community Connection: Do you feel connected  | 67  | 62.0 | 41 | 38.0 |
| to the community in which you live?  |     |      |    |      |
| 12. Safety: Do you feel safe in your community,  | 91  | 84.3 | 17 | 15.7 |
| family, or where you currently live?   |     | 50.0 | 50 | 40.4 |
| 13. Behaviours/Social: Do you have any   | 55  | 50.9 | 53 | 49.1 |
| behaviours that you know are not good for you that   |     |      |    |      |
| you would like to change or talk about?  | 72  | 67.0 | 26 | 22.0 |
| 14. Cultural: Do you feel you need more opportunity to learn and share your Aboriginal   | 73  | 67.0 | 36 | 33.0 |
| culture?   |     |      |    |      |
| Other concerns: Do you have any other concerns   | 18  | 16.5 | 91 | 83.5 |
| or needs that we have not covered yet?   |     | 10.0 |    | 55.5 |
| - man n - man - ma | 1   |      |    | 1    |

Facilitators reflected on use of the screening tool and felt that people were receptive and engaged and used to being asked questions so were comfortable with the process.

"I only have one story of one person in my entire Cultural Pathways Program time that had an adverse reaction to the screening tool...and that was quite a significant event.

Besides that, everyone else I spoke to engaged quite freely in the process".

#### - Facilitator

Facilitators regularly reflected about the utility of the tool to ensure they were able to get the most from it. An example of this was after using the tool for about 6 months it became evident to one of the Facilitators that many participants were answering no to the material circumstances question in the screening process but upon further discussion it would become evident that there was often stress and worry associated with making payments on very large bills without any essential services being disconnected. The question was adapted to better reflect peoples lived experiences. The material circumstances question changed from "In the last twelve months have any of your essential services been disconnected?" to "In the last 12 months, have you received a bill and been worried about how you are going to pay it?". As part of the reflective approach the use of the screening tool was discussed regularly over time, with it being evident that the tool enabled conversations about participants needs and was easily implemented to identify needs and inform the goal setting process.

# Strengths-based case management

A total of 3,808 interactions occurred with program participants (Table 5.2.8). Of these, 2,131 phone calls were made to participants and of these phone calls, 972 (42.9%) were successful and 1,292 (57.1%) were unsuccessful or no contact was made with the participant. High rates of 'text messages sent' reflect their utility for contacting participants to introduce the Program/Facilitator. After initial contact with a participant, if it was agreed upon as a preferred communication method, text messaging was used to check in, provide information, and arrange meetings.

Table 5.2.8: Interactions with Participants by mode of contact

| Contact Mode          | N    | %     |
|-----------------------|------|-------|
| Phone call made       | 2131 | 56.0  |
| Phone call received   | 166  | 4.4   |
| Text message sent     | 877  | 23.0  |
| Text message received | 100  | 2.6   |
| Letters sent          | 161  | 4.2   |
| Letters received      | 4    | 0.1   |
| Email sent            | 206  | 5.4   |
| Email received        | 41   | 1.1   |
| Home Visit            | 73   | 1.9   |
| Face-to-face meetings | 47   | 1.2   |
| Case conference       | 2    | 0.1   |
| Total                 | 3808 | 100.0 |

Facilitators felt the programs approach to engagement was strategic and effective, striking the right balance.

"I mean nobody ever said they felt harassed. Yeah. I think it was cool in that when we implemented the text message beforehand, we found that we got more. And that's something that I implement in my job now to, so that it is a very good strategy because people hate answering their phones. I don't know. I think that people felt harassed or if they did, they just didn't answer their phone."

#### - Facilitator

"I don't think anyone felt humbugged so that's good. I think we had a very strategic approach that we thought about and piloted before we implemented it."

### - Facilitator

The content analysis of mental health needs highlighted that where approaches were participant led these were associated with the most documented outcomes (n=6) and the least undocumented instances (n=1). In instances where approaches were Facilitator led there was no outcome (n=2) or documented outcome (n=4) to the connection brokered. Partnership approaches, where Facilitators worked side-by-side with participants resulted in documented outcomes for three participants. In these instances, outcomes were not documented for and non-documented for two participants. The benefits of an empowerment approach were reiterated through participant yarns which emphasised the importance of feeling like they were getting 'a helping hand to step forward instead of just giving you what you need. You're not gonna learn anything if someone just does it for you. You need to learn with them." (Program Participant). Participants further highlighted the importance of the relationship with the Facilitator and the support from someone 'who cares':

"You see, it was like a lot of times I think it's for your own mental thinking, a lot of times you think people don't care. But when you get programs like that, there are people who are caring."

- Program Participant

"Um. She made you feel wanted. You know that it's just the way that she rings up all the time and checks on you and all that you know I've never seen a program that does that."

— Program Participant.

A hell of a lot more. Yeah, I felt good about myself that there was someone who cared there. Well, I don't think you can get any better than that. What [Facilitator] would be, yeah, because he went out of his way. He goes out of his way for the little fellows .. But fellows they don't know about things like that until they're introduced to it. I can't remember how I was introduced to [Facilitator], but I'm just so glad I was."

# - Program Participant

Yarns with participants highlighted the strengths-based empowerment approach can alleviate the shame about seeking certain types of services such as emergency food relief "You know, I never really rang them places because being shame and all that but she said, no its not being shame that's what they get funding for. I can ring them places now where I was too shame to before and I was thinking nah shame job, salvos and that you know, shame job you know." (Program Participant) or about their cultural identity and connection. "My skin colour, it did not matter the amount of information I did or didn't have. It was like you are Aboriginal no matter what you like, you didn't choose it and you didn't choose to, like, let go of it. And that's like really, she kind of made it like really proud." (Program Participant).

Feeling safe, comfortable and having positive relationships between the Facilitator and the Participant, contributed to participants feeling supported and being more willing to share their struggles and engage in the support provided by the program.

"I think it's always that. Because people will open up more if they're comfortable.

They're not going to tell you things that, some because they might be ashamed, or they just don't want to tell you everything. But I think that's very important to be able to help people, is to get down exactly what they're looking for."

### -Program Participant

"But, you know, she tried it best, you know, and I thought, oh, maybe we could try this or this or this, you know, so, you know, she was quite supportive and everything that she tried to do for me anyway."

# - Program Participant

"I suppose more supported because, like I said, with the chatting and stuff like that and given the ideas of where you could go if you needed help with stuff, your mental stuff and smoking. I was struggling with smoking."

# - Program Participant

Participants highlighted the value of being able to develop a relationship with one person, to not having to re tell stories over and over and through that relationship being able to have flexible ways of engagement that most suited the participant.

"No, it was good to just have I suppose having that one person that OK, if you can email, phone wherever which way your preference is, at least that way you have got that one person to deal with instead of having. OK, I want to speak to this and okay I put you through that one. Yeah. Having that one person to do with all your bits that you need."

- Program Participant

# Achieving goals and priorities

Through the participant led goal setting process, the most consistently prioritised goal was material circumstances with 22.7% listing this as their priority 1 goal. The types of goals identified by participants are detailed in Table 5.2.9. Yarns with participants highlighted their experiences with pervasive unmet financial needs and from their perspective a need for a lot of help in relation to their financial circumstances with one participant describing that "I needed a lot of money help". (Program Participant) and another "I've always needed some kind of help...but finance, what type of finance can you steer me into?" (Program Participant)

Table 5.2.9: Goals identified by domain and order of priority

| Domain                       | Priority 1 |      | Priority 2 |      | Priority 3 |      |
|------------------------------|------------|------|------------|------|------------|------|
|                              | n          | %    | n          | %    | n          | %    |
| 1. Food Security             | 5          | 4.5  | 2          | 2.7  | 1          | 2.2  |
| 2. Material Circumstances    | 25         | 22.7 | 13         | 17.6 | 13         | 28.9 |
| 3. Health Care Access        | 12         | 10.9 | 11         | 14.9 | 3          | 6.7  |
| 4. Transport                 | 5          | 4.5  | 3          | 4.1  | 5          | 11.1 |
| 5. Housing                   | 12         | 10.9 | 10         | 13.5 | 5          | 11.1 |
| 6. Employment and Education  | 10         | 9.1  | 3          | 4.1  | 2          | 4.4  |
| 7. Literacy and Numeracy     | 3          | 2.7  | 2          | 2.7  | 0          | 0    |
| 8. Health                    | 13         | 11.8 | 9          | 12.2 | 8          | 17.8 |
| 9. Psychosocial              | 14         | 12.7 | 12         | 16.2 | 3          | 6.7  |
| 10. Family and Relationships | 0          | 0    | 3          | 4.1  | 0          | 0    |
| 11. Community Connection     | 3          | 2.7  | 1          | 1.4  | 0          | 0    |
| 12. Safety                   | 0          | 0    | 0          | 0    | 0          | 0    |
| 13. Behaviours / Social      | 2          | 1.8  | 2          | 2.7  | 0          | 0    |
| 14. Cultural                 | 6          | 5.5  | 3          | 4.1  | 5          | 11.1 |

Overall, 43 participants achieved identified goals upon leaving the program (Table 5.2.10). Reasons for closure included when unable to make contact, lost contact, participants declined, withdrew or where goals have been met (Table 5.2.10).

Table 5.2.10: Summary of Program Case Closures

| Case Closures       | n   | %    |
|---------------------|-----|------|
| Lost contact        | 41  | 35.3 |
| Goals met           | 43  | 37.1 |
| Goals partially met | 32  | 27.6 |
| Total               | 116 | 100  |

Challenges in program completion with goals met were evident from the early stages of the program delivery, with strategies and adaptations over time to respond. In the early stages of the program through program monitoring and reporting we noticed that many participants were in the "intake and screening" phase with there being a slow transition through each of the stages of the program delivery. Further, reviewing closures highlighted that there were few participants who had achieved goals, many were not contactable, and we also noticed quite a large number (more than expected given the need) declined. As a response we adapted the structure of weekly case discussions to greater frequency to increase opportunities to discuss each participant and plans to work towards outcomes to facilitate earlier identification of these trends. We reviewed and amended the first contact script to support better uptake at first contact and introduced text before calling. Facilitators undertook motivational interviewing training delivered by the local Health Department for Health Professionals but did not feel the skills they learnt were particularly helpful for the challenges they were continuing to face with moving people through the change process and motivating participants to stay engaged and tackle their more challenging goals.

Despite these developmental strategies, this remained an ongoing challenge highlighted by the example in the content analysis, where psychosocial needs were not always discussed despite being identified in the screening tool, the analysis found that 51 (61%)

participants had their psychosocial needs discussed at first meeting and recorded in ISBAR documentation and 33 (39%) did not. Program participants highlighted diverse unmet needs and consistently described their experience of 'stress' in different ways including; "Well, I have got no bills. Only thing I've got is the stress." (Program Participant) and "Yes. That's right. There are times, just times when, you know, I've never been so badly off. I guess there's quite a few people in my position now." (Program Participant). It was noted through the developmental approach that Facilitators were striving to maintain the integrity of the model by being participant driven and trying not to push too hard, especially given the unmet needs and stressors experienced by many participants and the risk of disengagement. The reflective approach highlighted that it was common for participants to address 1-2 goals fairly quickly and then lose momentum or take much longer on certain goals, particularly mental health and other challenging self-directed goals. Facilitators also described these challenges in the workshop session, that Participants did not always freely share psychosocial (mental health) information or prioritise mental health as a goal. Participants tended to identify the most pressing need for them, most often material circumstances (e.g. big bills) and then move on from the program.

### Service connections and accessibility

To facilitate connections to services a total of 720 interactions were undertaken on behalf of 116 participants. These interactions included phone calls, emails, face to face contacts, referrals and facilitation (Table 5.2.11). Facilitation included tasks which were undertaken as part of facilitating service connections, such as following up actions or completing requirements other than referrals.

Table 5.2.11: Interactions with Service Providers by mode of contact

| Mode of Contact      | N   | %    |
|----------------------|-----|------|
| Phone call made      | 133 | 18.5 |
| Phone call received  | 24  | 3.3  |
| Email sent           | 87  | 12.1 |
| Email received       | 94  | 13.1 |
| Face-to-face meeting | 16  | 2.2  |
| Case Conference      | 85  | 11.8 |
| Referral received    | 120 | 16.7 |
| Referral sent        | 42  | 5.8  |
| Facilitation         | 117 | 16.3 |
| Total                | 720 | 100  |

Service connections were measured through program indicators which are outlined in detail in the Cultural Pathways Program Protocol (Appendix 5.1) and summarised by domain in Table 5.2.12.

A total of 175 indicators were met by the program, including 16.4% (n=53) for material circumstances, 15.1% (n=49) for housing, 13.9% (n=45) for health and medical and 10.8% (n=35) were for psychosocial needs / mental health.

Table 5.2.12: Program indicators addressed by domain

|   | Indicators addressed |      |
|---|----------------------|------|
| Domain                                  | n                    | %    |
| Food Security                           | 14                   | 4.3  |
| Material Circumstances                  | 53                   | 16.4 |
| Health Care Access                      | 2                    | 0.6  |
| Transport                               | 14                   | 4.3  |
| Housing                                 | 49                   | 15.1 |
| Employment and Education                | 17                   | 5.2  |
| Health and Medical                      | 45                   | 13.9 |
| Psychosocial                            | 35                   | 10.8 |
| Family and Relationships                | 4                    | 1.2  |
| Community Connection                    | 29                   | 9.0  |
| Safety                                  | 2                    | 0.6  |
| Behaviours/Social                       | 20                   | 6.2  |
| Cultural and Community<br>Connectedness | 40                   | 12.3 |
| Other concerns                          | N/A                  | N/A  |
| Total                                   | 324                  | 100  |

Specifically for mental health needs Facilitators brokered a range of connections to services including community programs, counselling, provision of information, and referrals to General Practitioners (Table 5.2.13). For 23 (45.1%) participants there were no documented connections brokered.

*Table 5.2.13: Psychosocial connections brokered by the program* 

| Psychosocial Connections Brokered | N  | %    |
|-----------------------------------|----|------|
| Community Program                 | 2  | 3.9  |
| Counselling                       | 10 | 19.6 |
| Information Provided              | 9  | 17.6 |
| Mental Health Plan                | 1  | 2.0  |
| Referral to GP                    | 2  | 3.9  |
| N/A - Accessing Support Already   | 4  | 7.8  |
| None - No connection brokered     | 23 | 45.1 |
| Total                             | 51 | 100  |

Several participants described their experiences with mental health issues, with one participant highlighting how mental health significantly impacted their wellbeing and their ability to maintain or meet their basic needs, such as housing.

"I was dead, I was suicidal, everything, I moved out because of that. And I realised after I didn't have to. I gave up a lovely bloody house because of my anxiety attack because that lasted for two months. And every day I was having that attack, every day."

-Program Participant

The qualitative exploration of barriers and/or enablers to Mental Health Care Access recorded in case notes highlighted access barriers in relation to personal circumstances, particularly experiences of feeling overwhelmed, as recorded by a Facilitator where "Participant stated at that time she was overwhelmed and never went to her doctor to get the referral." Another example "Participant explained that she has not looked into carer support groups yet because Participant has "been so busy". Participant further explained that she is thinking about quitting her job as she feels like she doesn't have time to work and take care of her grandchildren." Other barriers to access were described through challenges with access, and that it is not always simple for participants to access the support required for their mental health needs, as evidenced in an instance where a Facilitator recorded "Participant was told she was not able to transfer to another counsellor. Participant advised that she was told she would need to go back to her doctor to get another referral for another counsellor." Yarns with participants highlighted that participants want to be able to access all services in the one place.

"Yeah, because before I was trying to be here, there and everywhere. I said to my doctor, for my mental health, and I can't get everyone to drive me everywhere, is there anywhere that I can go to the one place? And they sent me there, so I have been going there for the last year and a bit now."

### - Program Participant

The participant described being able to access all services (physiotherapist, psychologist, etc) in the one place but also described this as being temporary, as it was a private clinic the participant was able to access for a short time due to a work cover claim. Participants described frustration at barriers to access the services they need, described by one participant as:

"I was supported, but just when it come to the paperwork, and like trying to get into different avenues and stuff like that, it was just like we'd hit rock every time. Bang, bang, bang. And I could see it in his eyes, he'd get pissed off too, and he goes, oh why are these cunts doing this to us."

# - Program Participant

The importance of service accessibility was highlighted as an enabler, as evidenced when "Participant stated that he did not know that a service was so close to his house and would not have talked to them if Facilitator did not provide information of service to Participant" Facilitators described the challenges of working with complexity: "I think that was the hardest thing for me. Being a facilitator was to be like we've exhausted all these options and we barely put a scratch on the surface of these things that you're experiencing." It was also challenging when there were no options available for support: "I think it's hard. Sometimes it felt like we were just two people coming in, you know, people had seen it before and that we were trying to come and try and help them and ultimately, listen, I'm sorry. There's nothing we can do and see you later."

Participants identified that services need to sit down together and talk more to work together.

"If you could work something out with the program and the job networks and that, say get together or something, and say, look, this is really what he wants to do, how about you come across a bit and we'll see what we can do."

- Program Participant

### Documentation and Monitoring

The developmental approach was critical for the ongoing monitoring and evaluation of documentation and monitoring approaches and allowed for insight into activity, process and outcome documentation approaches and measures. The program adapted over time to include key performance indicators (KPI) which were developed to suit funding requirements and embedded into regular monitoring and reporting. The approaches implemented created opportunity for continuous improvement by reviewing data and adapting approaches. For example, a developmental approach involved adapting data collection early in implementation to enable 'type of contact' to be recorded as either direct with the participant or with a service provider. This was to reflect more accurately activity for brokering connections including activity directly with participants or on behalf of participants. Another example of an adaptation was the inclusion of successful or un-successful modes of contact, introduced after noticing high occurrences of activity that go into attempting to engage participants, the time and energy required of Facilitators so it should be accurately reflected as work/activity.

An ongoing observation was the complexity of "measuring" outcomes in relation to social and emotional wellbeing or the social determinants of health. The KPIs of the program did not measure an outcome and goals met were not always the most reliable. It was not uncommon for participants to address a need they did not identify as a goal, additionally goals were not consistently reviewed/revised. The mental health needs analysis highlighted that the unmet mental health / psychosocial needs were often not explicitly documented, and the database was not set up to document this. The type of disorders, the type of service connection made (counselling, mental health plan etc) could only be obtained from reviewing case notes, which while were required to follow a standardised format are subjective and details documented can vary depending on the Facilitator and their training/experience. The outcome was documented for 11 out of 23 participants where connections were made (Table 5.2.14). In many instances the outcome was not documented in the notes or the outcome was unknown due to losing contact with the Participant (Table 5.2.14).

Table 5.2.14: Engagement with mental health support services brokered by the program

| Engagement with Support brokered by the program | n  | %    |
|---|----|------|
| Yes   | 9  | 39.1 |
| No  | 2  | 8.7  |
| Not Documented                                  | 6  | 26.1 |
| Unknown/Lost Contact                            | 6  | 26.1 |
| Total   | 23 | 100  |

There were four Participants who engaged in support / or were engaging in support not brokered by the program (Table 5.2.15).

Table 5.2.15: Engagement with mental health support services not brokered by the program

| Engagement with Support not brokered by the program | N  | %    |
|---|----|------|
| Yes   | 4  | 10.5 |
| No  | 0  | 0.0  |
| Not Documented                                      | 31 | 81.6 |
| Unknown/Lost Contact                                | 3  | 7.9  |
| Total   | 38 | 100  |

Yarns with Facilitators confirmed what was highlighted in the SOAP note content analysis, that participants had varied responses to the psychosocial question. Some quite openly spoke about their unmet needs, and were aware of what they needed. This awareness made it easier to discuss and to put plans or goals in place. Others discussed stress more broadly and did not always set it as a goal. The Facilitators also highlighted that neither felt the program or their role/training/scope of practice were designed to be able to help participants so often plans were put in place when participants were more actively discussing mental health/psychosocial needs.

"Thinking back to a few clients, I think what the downfall was, was there was a lot of yeah, yeah, yeah. And then I would connect the men and then they wouldn't answer their phone or they wouldn't go to the appointment. In the end I was never quite able to find out.. Was it lack of transport? Is it because you just really don't give a shit about it or is it there's something else going on that perhaps we need to address so that getting them to go from the contemplation stage to the to the next one". – Facilitator

# Workforce and Yarning Support

Facilitators positively reflected on the support they received. Key points they highlighted included that the "supervisor" was nice and there was a relationship that was not hierarchical, so Facilitators felt safe to share, because they did not feel there was a risk to their employment or their job role if they expressed that they were struggling. Facilitators felt it was absolutely necessary that a line manager did not provide this yarning support as it allows for a balanced dynamic (removes power) and they felt they could be honest and get support for what they needed. Facilitators felt that preferably an Aboriginal person should deliver support because they already get the every-day context and it doesn't have to be explained as well as having service delivery experience / clinical experience because then the 'supervisor' can relate to the experience of Facilitators.

"that you've worked on the ground, you know the grind, you know the shit we're up against, the people, participants are up against and so being able to relate to that so easily that also helped." - Facilitator

### 5.2.4 Discussion

Chapter Five has demonstrated an approach, implementation insights and the results from the evaluation which include process indicators, participant experiences and facilitator perspectives. There are key elements (described in detail in 5.1) which when combined can form action in practice on the social determinants of health. Applying these elements in a research setting has enabled evaluation to strengthen understandings of these elements and their practice applications. The key learnings and insights for each of these elements is described throughout this section.

### Screening for unmet needs

Findings from Chapter Five provide an understanding of the broader social and cultural domains which are relevant for Aboriginal and Torres Strait Islander community and the extent to which these unmet needs are experienced by program participants. The screening tool was developed as a social and cultural determinants of health screening tool with domains encompassing social and emotional wellbeing factors. The tool was used with over 100 Aboriginal and Torres Strait Islander participants, and while not empirically validated, from the perspective of Facilitators who implemented the tool with participants, it was accepted and effective for identifying the unmet social and cultural needs of participants. The results of the evaluation highlight participants experience multiple complex and interconnected unmet social and cultural needs which were identified through the screening process. This complexity was observed in the translation of ADS participants (n=350) who identified unmet needs and were referred to the program compared to those the program was able to engage for screening and subsequent support (n=116). The screening tool responds to a considerable evidence-based practice gap where currently there is no routine or systematic screening for social and emotional wellbeing needs (Gupta et al. 2020). The tool can enable a screening approach to more targeted health or condition specific assessments. Through evaluating the implementation of the tool in the program and current translation activities for use more broadly in health settings, the tool can support the systematic screening and identification of social and emotional wellbeing needs for Aboriginal and Torres Strait Islander peoples.

Existing evidence highlights current approaches to health assessments for Aboriginal and Torres Strait Islander populations are not designed to identify the breadth of social and emotional wellbeing needs, including the social determinants of health (Bailie et al. 2019; Langham et al. 2017; Spurling et al. 2017). Current approaches continue to emphasise biomedical needs which is contradictory to Aboriginal and Torres Strait Islander social and emotional wellbeing (Spurling et al. 2017). Examples of this are evidenced through a focus on condition specific screening. The National guide to preventative health assessment for Aboriginal and Torres Strait Islander people: 3<sup>rd</sup> edition (National Aboriginal Community Controlled Health Organisation 2018), provides the framework for health checks and embeds the social determinants of health in specific conditions. As an example, rheumatic heart disease assessment questions and interventions include the social determinants of health explicitly as these are well established to adversely affect the condition, however through this embedded approach it fails to recognise the interconnected and inter-related aspects of wellbeing across conditions (Bailie et al. 2019; Spurling et al. 2017). Further, some attention has been invested in research and practice to develop and validate psychometric tools, such as the Aboriginal PHO-9 and the Here and Now Aboriginal Assessment (HANAA). The Aboriginal PHQ-9 is specifically designed to screen for depression and does not include holistic socio-cultural factors, while HANAA covers a range of domains specific to physical health, sleep, mood substance use, life stressors and resilience, it does not emphasise or capture combined bio-psycho-socio-cultural factors (Janca et al. 2015; The Getting it Right Collaborative Group 2019). Culturally relevant health assessments can offer improved opportunities for preventative care (Bailie et al. 2019), and culturally developed and/or adapted tools have the potential for greater clinical effectiveness as they better align with social and emotional wellbeing and Aboriginal Torres Strait Islander views of health (Janca et al. 2015; The Getting it Right Collaborative Group 2019). Screening across the breadth of social and emotional wellbeing domains, including the social determinants of health must be applied in practice to support more systematic and coordinated approaches to care, and also to facilitate/enable the ability to measure activity, progress and outcomes. Screening at the point of care, can support early engagement and continuity of care without needing to make another referral which may be the difference between keeping people connected or not.

# Strengths-based case management

# Participant engagement

Evaluation findings highlight participants appreciated the approach which as flexible, strengths-based and participant led. Participants valued having one key contact they were able to build a relationship with. From the onset of program development, a strengths-based approach was articulated and there was a purposeful commitment to move beyond rhetoric and ensure that this was both a philosophy of the program and something which was practiced, that strengths-based approaches were given life in program implementation. These strengths-based approaches outlined in the Cultural Pathways Program Protocol (Appendix 5.1) and implemented in practice have been summarised and synthesised as guiding principles and ways of working below:

# Cultural Pathways Program Guiding Principles and Ways of Working

- Aboriginal and Torres Strait Islander holistic social and emotional wellbeing
  - O Program philosophy underpinned by the social and emotional wellbeing framework and interconnected domains of health and wellbeing which is embedded in program protocol, tools and approaches (culturally developed and relevant tools, holistic screening tool, goals, ways of working).
- Strengths-based tools, approaches, and ways of working.
  - o Program philosophy underpinned by strengths-based theory.
  - Embedded into tools and approaches (use of AIMhi care planning documents including the *growing strong tree*, goal setting approaches and ways of working).
- Participant led, empowerment focused and flexible.
  - Building capacity of participants through ways of working that focus on empowerment through tools and approaches.
  - Flexible Approaches to engagement and responding to individualised needs. Embedded into tools and approaches (ways of working with participants – being participant led, letting them guide what was done, when and how, taking a flexible approach to contact through text, phone

- or participants preferred way of communicating, built into program protocol to support application in practice).
- Walking with / working in partnership with and staying with participants, however long it takes. Embedded into tools and approaches, for example, participants decide when they are ready to move on.

As a key output of the evaluation these documented principles and ways of working will be utilised by program funders, the Wyatt Benevolent Institution, known as the Wyatt Trust. The Wyatt Trust is a philanthropic organisation supporting South Australians since 1886 with a primary aim to alleviate poverty and more recently to focus on system changes and inequality in addition to the provision of small grants and financial relief to individuals. The Wyatt Trust has a Reconciliation Action Plan (RAP) and has been working towards truth-telling and more meaningful and genuine engagement with Aboriginal and Torres Strait Islander communities (The Wyatt Benevolent Institution Inc. 2021). As a first-time partnership between the Wyatt Trust and Wardliparingga, these principles, ways of working and evaluation findings more broadly have the potential to influence the work undertaken by the Wyatt Trust with Aboriginal and Torres Strait Islander communities into the future. The organisation requested a practical output that could inform their work and the philanthropic context.

A focus on strengths is strongly articulated in key Aboriginal and Torres Strait Islander health policies/plans as necessary for improving Aboriginal and Torres Strait Islander health and wellbeing (Commonwealth of Australia 2017; Department of Health 2021). As previously highlighted in this chapter there is a gap between talking about strengths-based practice and implementing strengths-based practice (Askew et al. 2020). An example of this can be found in the *National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people* (National Aboriginal Community Controlled Health Organisation 2018), which despite the strong articulation of the need for these strengths-based approaches, does not detail any guiding principles or applied ways of working within the guide. This example highlights that there are still few practical and applied examples in the literature to support 'doing' or implementing strengths-based principles and ways of working in practice.

Strengths-based approaches contribute to increased resilience and can enhance motivation, sense of control and support identification of challenges and barriers which all contribute to improved wellbeing (Gupta et al. 2020). The findings of the evaluation can contribute to and inform the emerging evidence to transform intentions of strengths-based practice into action. These include the programs theoretical grounding (holistic, strengths-based, empowerment) and applied flexible approaches to engagement (strategic calls, texts, staying with people for as long as it takes, being prepared to walk along-side people, building capacity, focussing on strengths and abilities). The tools and approaches implemented by Facilitators to support participants with their goals all embed culturally relevant and strengths-based approaches into practice. The program did not measure specifically the impact of these approaches on outcomes, however based on the results (program data, reflections of delivery and yarns with participants) it is indicative that this approach was instrumental in achieving engagement with participants.

#### Goals and Priorities

The framework implemented in the program highlights that the process of self-identified priorities was of benefit to participants and Facilitators, which is consistent with evidence indicating needs and goals are best defined according to unique needs of individuals (Hurn, Kneebone & Cropley 2006). In developing the program approach for goal setting and prioritisation there were few goal setting frameworks for Aboriginal and Torres Strait Islander health and social service provision (Nagel & Thompson 2007). Existing evidence for goal setting is limited and usually specific for health conditions or fields of practice, such as mental health, despite these approaches being very common and considered to be successful/useful in practice (Clarke et al. 2009). There is little evidence on participant led goal setting processes and whether they increase the likelihood of achieving the outcome (Clarke et al. 2009; Hurn, Kneebone & Cropley 2006). The participant led process implemented in the program supported Facilitators to ensure the intervention was meeting participant needs. Program implementation highlighted that goals were challenging to use as an 'outcome measure' because they may change, or participants could address things "within" the goal, so they were often very fluid. Whilst the dynamic nature of goals can make measuring outcomes or attainment challenging, goal attainment scales have been used to effectively measure goals as an outcome (Hurn, Kneebone & Cropley 2006).

The program approach to developing and documenting goals provided insights into the needs of participants, supports implemented in response and outcomes of the goal and was a form of ongoing quality improvement. Future implementation of such approaches could be enhanced by considering goal attainment scales to strengthen the ability to use goals as an outcome measure. Evidence specific to Aboriginal and Torres Strait Islander wellbeing and case management programs can more clearly articulate goal setting processes offered to participants, the benefits and effectiveness. Insights from the developmental approach in this program point towards the benefits of an active relationship with goals which includes amending, changing, and achieving them to making them more 'living' in program delivery. This can enhance the potential for goals to inform ongoing implementation and monitoring and to also assist Facilitators to keep participants engaged and motivated to achieve the goals they identified for themselves.

# **Brokering Connections**

Through implementing the broker and connect approach in the program, the developmental insights highlighted that Facilitators often supported people with needs most important and/or immediate for them. The program supported high proportions of participants with material circumstances needs, however, to address this need there were limited options beyond applying for small grants through NGOs and philanthropic organisations and/or making connections to financial counselling services. The programs brokering model also noted these similar challenges for unmet housing needs and systemic housing issues. Limited access to public housing, shortages of rental properties and increasing costs of rental properties create a challenging environment for obtaining stable and secure housing (Andersen et al. 2016). Program Facilitators and Participants were often left frustrated with the lack of options to address housing needs and the intensity of effort that goes into supporting participants, and for participants themselves, to attempt to secure stable housing. System issues were particularly evident in these two examples, highlighting that it continues to be necessary to make explicit these complex issues which impact people individually and remain challenges for individual services to address.

# Complex Challenges

The developmental evaluation and content analysis highlighted that the program did not always facilitate connections for unmet psychosocial needs despite 84 out of 116 participants identifying this need. Many participants experienced multiple and interrelated unmet needs, as highlighted in the screening tool findings participants identified an average of 8.4 unmet needs out of 14 domains. Often, Facilitators were able to support participants with their most pressing needs, such as material circumstances, and then upon completion participants would not continue or Facilitators would lose contact with Participants. This was evident for mental health where the content analysis identified that participants often disengaged upon completion of a referral and that the program often faced challenges with 'lost contact' or with participants deciding that upon receipt of the referral / or information about a service they had received all they needed from the program and no longer wanted to continue. The intent of the program was to practice warm/active handovers once connections were brokered however staying with people, or keeping people engaged with the program, to ensure they achieve the outcome, and that we could record the outcome proved more challenging in practice than anticipated. The complexity and challenges of keeping people engaged was also evidenced in the significant drop off rate of referral from the Aboriginal Diabetes Study to being engaged as a Cultural Pathways Program participant. The participant led process meant Facilitators always followed the lead of participants, however the program findings highlight the important need to strike the balance between being participant led and ensuring participant needs are met whilst also enabling the program to monitor and record outcomes.

Mental health influences peoples' ability to address and engage many other domains of their wellbeing and there is a complex and inter-related relationship between mental health and other domains of wellbeing (Kowanko et al. 2009). Program findings, particularly for mental health needs highlight that screening or asking the question is not sufficient to successfully broker connections to services, and even further, ensure these brokered connections turn into outcomes for participants. It is critical that approaches consider how to engage people with multiple complexities and unmet needs and keep them engaged to ensure they can see improvements in unmet needs and to have the greatest impact.

# Systemic Challenges

Throughout the implementation and evaluation of the program a range of challenges were encountered regarding underlying systemic challenges in relation to financial and housing insecurity. The program findings are consistent with existing evidence which highlights that financial counselling has benefits for reducing financial stress, particularly for building skills for budgeting and planning and advocacy for hardship plans or debt waivers (Brackertz 2014). Across Australia people most commonly access financial counselling for utility bills (Brackertz 2014). However, existing policy efforts which focus on individualised skill development, budgeting and planning do not recognise structural issues facing those living with poverty such as very low incomes and high energy costs (Brackertz 2014). There is a need for multi-layered responses which address the causes of poverty including advocacy for increased allowances, and better service coordination and/or access to culturally relevant financial counselling and support (Brackertz 2014; Fan 2013). Housing availability, security and affordability challenges are facing many Aboriginal and Torres Strait Islander people and housing needs of Aboriginal and Torres Strait Islander people continue to go largely unmet by health/social policy and practice (Andersen et al. 2016). Housing and health for Aboriginal and Torres Strait Islander people has largely focused on environmental housing factors, and while important, there are other factors which contribute to healthy housing (Mansour et al. 2022). Housing issues which relate to availability, access and security are systemic issues which require a systemic response (Jacobs 2015). Complex system challenges such as housing and financial insecurity are not solvable at the individual or organisational level and these require systemic approaches. Unravelling these complex systems, advocacy to decision and policy makers are required in addition to the approaches outlined throughout this chapter which address unmet social and cultural needs.

## Documentation and Monitoring

The pilot program measured an 'outcome' upon brokering a connection and while this is sufficient for understanding if the program was achieving its intended objective, it did not measure the impact of the program on holistic health outcomes and with no existing measures specifically for social and emotional wellbeing this is critical for future research and/or practice implementation (Langham et al. 2017). The program evaluation

highlighted that documentation could be further enhanced for specific unmet needs, for example when mental health is identified it generates a set of questions to record the history, disorder. This would increase the potential to monitor these more specific needs at an aggregated level without having to access individual case notes to find information. This could enhance the process in practice to ensure unmet needs are discussed with enough detail and tracked over time.

Health record systems do not routinely document the level of activity undertaken to respond to social and emotional wellbeing / social determinants of health and existing practice approaches vary significantly across contexts (Bailie et al. 2019; Langham et al. 2017). While there is a growing body of evidence to support social and emotional wellbeing approaches (Gupta et al. 2020; Haswell et al. 2009), evidence of what and how to record this activity is scarce. Without relevant and systematic recording and documentation it creates challenges for ongoing quality improvement and to be able to advocate for adequate resources, review outcomes and adjust approaches, workforce and training as required (Bailie et al. 2016). Existing evidence calls for clearer guidelines and indicators (Bailie et al. 2008; Langham et al. 2017).

Facilitators described data collection processes as suitable, and they did not express any negative concerns. Facilitators were heavily involved in the development of documentation processes and requirements including the database which may have influenced their positive perceptions and experiences. The approaches implemented in the program provide practical examples of how to document social and emotional wellbeing activities, highlighting potential measures of activity and outcome which can be implemented in systematic and coordinated approaches. A limitation of the program and existing evidence more broadly is in being able to clearly demonstrate the relationship or impact of practice models on health outcomes (Reeve, Humphreys & Wakerman 2015). This is particularly challenging for social and emotional wellbeing where there is no specific outcome framework and with varied approaches taken and implemented to measure wellbeing. Existing approaches predominantly focus on instruments which measure conditions (e.g depression and anxiety) or psychological distress more broadly but do not capture the full spectrum of wellbeing domains, including the social determinants of health (Gupta et al. 2020; Langham et al. 2017). Through effective translation of findings from the program evaluation of 'what works' to document social

and emotional wellbeing activity, the findings can inform recommendations for future research and inform the development of 'harder' outcome measures.

# Workforce and Yarning Support

The program implemented yarning and workforce support. To avoid the negative connotations associated with language and the inevitable hierarchy of supervisor and supervisee relationships there was an early decision to move away from language of supervision despite being originally used. When used in practice the program team used "yarning" to better reflect the connected, reciprocal and relationship-based nature of the approach (Bessarab & Ng'Andu 2010; Geia, Hayes & Usher 2013; Lin, Green & Bessarab 2016; Stargell et al. 2020). Reflections over time align this model towards a more therapeutic relationship aimed at 'healing workforce' with culturally embedded approaches and alignment with creating safety (Stargell et al. 2020). This workforce model was delivered by the evaluator, with expertise and experience providing clinical supervision to Aboriginal and non-Aboriginal workforce practising in health worker, support worker, and social work roles. This approach was implemented with a small sample size of Facilitators with feedback provided directly to the evaluator throughout delivery and in the workshop. Acceptance of the approach, positive feedback and the absence of any negative feedback (noting that there were opportunities for Facilitators to provide external feedback if they did not feel the model was safe or appropriate), highlight acceptability and valuable insights from the approach which would warrant further exploration.

This aspect of the evaluation drew heavily on reflective practice and insider approaches, as the evaluator TB engaged in two roles, one as a clinical supervisor discussing practice and the needs and experiences of Facilitators which impacted upon their practice and secondly, by engaging in reflective practice about the program's implementation and delivery from an evaluation perspective. As part of this approach, TB was able to facilitate discussions with program Facilitators and create a space for ongoing reflection about what was happening for participants, Facilitators, systems and contexts and making adaptations to the program delivery as needed or recording important considerations over time. From this reflective approach evaluator observations were that this model created a safe and supportive dynamic, by developing a relationship which was non-hierarchical and

utilising a range of techniques, including counselling, deep listening, yarning and relationality. Over time this relationship was strengthened allowing for challenging and supportive conversations to occur. This is consistent with the direct feedback from the perspective of Facilitators throughout implementation and in the workshop with Facilitators that they felt supported in their role, and they valued the non-hierarchical, relationship-based approach.

Evidence indicates the Aboriginal and Torres Strait Islander workforce experience a range of complexities as part of their roles with community and require support for healing and holistic wellbeing (Eades et al. 2021; Schultz 2020). The relational nature of Aboriginal and Torres Strait Islander communities means that often the workforce are closely connected to and deeply feel the challenges the community they support are facing (Lauw et al. 2013). This interconnected relationship between the worker and the community can lead to a higher likelihood of burnout or vicarious trauma (Devilly, Wright & Varker 2009; Eades et al. 2021). The challenges facing communities are often carried with the workforce as they go about their work which requires support (Eades et al. 2021; Schultz 2020). An enhanced understanding from the workforce, supported through their workplace, of their own lived experiences, histories and how these impact on their practice is critical. Creating safety allows practitioners to be vulnerable, to share these challenges openly, and to heal, which increases capability in their clinical role (Lauw et al. 2013; Schultz 2020; Stargell et al. 2020). In addition to quality relationshipbased and safe support, wellbeing workforce models need to consider job roles and descriptions, tools and resources and the training and development needs of Aboriginal and Torres Strait Islander workers (Deroy & Schütze 2021). Non-Indigenous workforce also require access to ongoing professional development and quality cultural supervision to increase their cultural knowledge and facilitate safer practice (Oates & Malthouse 2021). Approaches based on relationships and safety also support the non-Indigenous workforce to support ongoing reflection and development (Stargell et al. 2020).

This therapeutic approach to workforce support created opportunities for quality on the job professional development, particularly to have 'hard conversations' or to work with 'complex issues' which are often part of these roles. Whilst these understandings and experiences have been invaluable and provided important insights into workforce

support, the small team and context in which this model was provided means that these are generalised conclusions and necessitates that these insights and learnings need to be applied in different contexts and further explored and appropriately evaluated. This would enable this model to be further developed and utilised across a range of sectors to support Aboriginal and Torres Strait Islander workforce.

# Emergent 'Practice Framework'

This chapter has highlighted that evaluation findings are comprehensive across a range of program elements. Many of the findings have provided a necessary foundation for future research and opportunities to consider what an emergent practice framework for taking action on the social determinants of health would look like. The evaluation has highlighted areas to be extended including the need to apply these elements in 'real world' contexts, to consider moving beyond brokering connections in a broken system. Whilst essential to connect people to services which meet their needs, the system limitations and challenges to partnerships between services mean that brokering connections is providing temporary relief but not addressing the causes, of the causes (Anderson, Baum & Bentley 2004; Osborne, Baum & Brown 2013). Therapeutic interventions, through connection to Country, culture and healing opportunities, may support programs to address immediate and basic needs (e.g material circumstances) while working towards greater wellbeing. Underpinning all of this is an opportunity to implement workforce healing models for a supported, strong, connected and well Aboriginal and Torres Strait Islander workforce, which benefits the workforce and the community they serve.

## 5.2.5 Conclusion

Chapter 5.1 established that there is an evidence and practice gap on how to address the social determinants of health and holistic wellbeing needs of Aboriginal and Torres Strait Islander people and communities. Whilst many of the approaches described are implemented in various ways in current practice, including routine screening for unmet needs, implementing strengths-based practice, connecting people to what they need, monitoring service provision and providing clinical and cultural support for the Aboriginal and Torres Strait Islander workforce. It is the combination of these approaches into the Cultural Pathways Program model of care which enables these elements to translate into existing practice which is transferable across contexts.

Chapter 5.2 describes the program evaluation methods and findings for these practice approaches to contribute to practice-based evidence of culturally relevant case management approaches providing a framework to inform service planning and tailored implementation which can strengthen social and emotional wellbeing responses for Aboriginal and Torres Strait Islander people. The findings of the evaluation provide valuable insights into the next steps for each of the approaches. By implementing these approaches services can work towards consistent and coordinated approaches which are supported by data systems, monitoring and continuous quality improvement that allows them to respond to holistic wellbeing needs as part of routine care.

The program implementation delivered in a research setting requires expansion of the scope to consider the relevance and success of the applied approaches in different practice settings with different populations and needs. The findings described are foundational across a breadth of areas, more rigorous exploration for many of the elements and approaches is needed. The findings provide a sound starting point and foundation to enhance the approaches to suit context and to move towards a focus on monitoring or measuring the impact of such interventions on health outcomes. In being able to measure this impact Aboriginal and Torres Strait Islander communities and the services which support them are better able to advocate for responses which meet their needs and to more clearly target and prioritise areas of need, reducing the stress of "doing whatever it takes" without really understanding what that is and how to best do it. The 'social factors' or the social determinants of health remain elusive and challenging without structures and approaches to respond to them systematically.

# CHAPTER 6: INFORMING ACTION IN PRACTICE ON THE SOCIAL DETERMINANTS OF HEALTH AS PART OF SOCIAL AND EMOTIONAL WELLBEING

# 6.1 Synthesis of Thesis Findings

The findings of this program of work align with aspirations and priorities of Aboriginal and Torres Strait Islander communities that include culturally safe systems equipped to provide holistic culturally responsive services to promote social and emotional wellbeing outcomes. This chapter outlines key findings of this work including Aboriginal and Torres Strait Islander ways of knowing, being and doing in describing the social determinants and mental health needs, understandings of health program approaches and the ways of working which can be implemented in practice to address the social determinants of health. This chapter highlights the practice, methodological and theoretical considerations of this program of work and outlines knowledge translation activities and future research recommendations to build upon the foundation for action on the social determinants of health.

The PhD program of work had three studies: to understand the need (Study 1), what is being done (Study 2), and how to take action (Study 3). Study 1 highlighted that mental health rates and social determinants of health outcomes were consistent across all local geographic regions (Landscapes) in South Australia. There were proportions of 50% or less for those in employment, with incomes above the poverty line, and with year 12 attainment. Evidence which highlights the impact the social determinants of health can have on health and wellbeing outcomes would indicate that there are vast unmet needs for Aboriginal and Torres Strait Islander people in South Australia (Markwick et al. 2015). Study 2 highlighted few programs which specifically aim to address the social determinants of health. Scoping review findings highlighted a lack of systemic or coordinated action, with the majority of programs provided in different contexts, with varied intentions, addressing a diverse range of health needs. Included programs were delivered in Aboriginal Community Controlled Health Organisations (ACCHOs) or by Government health service providers. Programs were often inter-disciplinary, and many made implicit references to the social determinants of health, such as describing 'socioeconomic' factors. The results of the scoping review indicate a need for a more explicit and shared language to be used in program implementation and to describe these programs in the evidence. Study 3 through implementation in practice and evaluation of a strengths-based case management model contributes to significantly lacking practicebased evidence. This thesis in conceptualising and articulating complex and interconnected social determinants of health as part of social and emotional wellbeing

supports understanding which include cultural, structural, and environmental determinants. Through a clear conceptualisation and articulation, the social determinants of health become more consistently described and understood contributing to a greater potential for action in practice to address them.

## 6.2 Practice Recommendations

This work has a translation focus which is consistent with evidence-based practice, implementation science approaches and the underpinning Indigenous methodology. This work contributes to informing health service practice which addresses the social determinants of health as part of promoting social and emotional wellbeing. The innate intention to undertake research for the benefit of community required a focus on factors across multiple levels, including individuals, service providers, organisations, the broader community, and policy context (Bauer et al. 2015). A significant contribution of this program of work is the dynamic way the connection between evidence-based practice and practice-based evidence has been utilised to both inform and be informed by existing evidence. The following section emphasises the key considerations and insights to these practice-based understandings as well as highlighting areas requiring further research and a range of recommendations.

Ways of Knowing: Social and Emotional Wellbeing and the Social Determinants of Health

From the outset of this project, it became evident that there were a range of complexities relating to the way the social determinants of health are understood, conceptualised, and described both globally and locally. For Aboriginal and Torres Strait Islander people, complexity is added when aligning global understandings of the social determinants of health with Aboriginal and Torres Strait Islander knowledges and definitions of health and wellbeing. The conceptual approach of this program of work utilised Gee and colleagues' social and emotional wellbeing framework (Gee et al. 2014), which includes the social determinants of health. Social and emotional wellbeing, or holistic health understandings, despite being first articulated as part of the National Aboriginal Health Strategy Working Party (NAHSWP) (1989), are often inconsistently understood and described in evidence and practice. Social and emotional wellbeing is increasingly referenced in policy, plans and service delivery. However, social and emotional wellbeing and mental health are often conflated and there continues to be an emergence of different models and frameworks for the social determinants, cultural determinants, and social and emotional wellbeing (Bourke et al. 2022; Lovett et al. 2020; Salmon et al. 2019; Williamson, Dent & Bowman 2021). While many of these models and frameworks make important evidence-based contributions and underlying conceptualisations, definitions and meanings align, the current absence of a single or universally agreed

conceptualisation will continue to pose challenges. Further adding to the complexity of cultural understandings is when looking more closely at the social determinants of health, in policies, plans and health reports there are varied ways these are described, there are variations in the domains which are included as social determinants or not, and there is varied language to describe them, such as social factors, socio-economic conditions and so on. These factors contribute to confusion and complexity in conceptualising and subsequently articulating social and emotional wellbeing and the social determinants of health, with a lack of clarity contributing to challenges for coordinated research, policy and practice approaches.

It is difficult to measure activity, or impact and outcomes if there is no clear and consistent framework to build these metrics against. The conceptualisation of the social determinants of health in this program of work aligns with Indigenous knowledges and definitions of holistic health. To support a more culturally aligned conceptualisation, The Aboriginal and Torres Strait Islander Health Performance Framework (HPF) (Australian Institute of Health and Welfare 2020a) measures were utilised as a guide for conceptualising the social determinants of health. The HPF as a conceptualisation for the social determinants of health has some limitations, however in the absence of an explicit conceptualisation approaches such as these are necessary. This program of work in its attempt at a clear conceptualisation, while consistent with the World Health Organisations (WHO) (Solar & Irwin 2010) conceptualisation, still required adaptation depending on the study, the available data, and consistency with Indigenous knowledge and understanding. Study 2 review findings highlighted the need for a call to action to name, label and measure the social determinants of health in health service delivery and research with Aboriginal and Torres Strait Islander people and communities. Study 3 in operationalising the social determinants of health as part of social and emotional wellbeing enabled culturally aligned understandings.

Box 6.1: Practice Recommendation 1, clear and consistent conceptualisations

Recommend clear and consistent conceptualisation and articulation of social and emotional wellbeing and the social determinants of health in policy and practice for Aboriginal and Torres Strait Islander people.

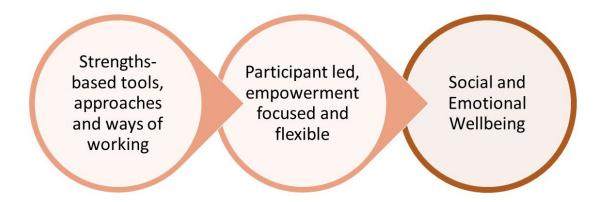
#### Expanding on Practice-Based Evidence

Aboriginal and Torres Strait Islander communities are well known to have been extensively 'researched' and in consideration of this, the approach of this work did not 're-invent the wheel' and was informed by existing evidence-based practice approaches to case management and program implementation. The types of variables and understandings which would be explored in the scoping review (charted data) and in the development of the Cultural Pathways Program (the program elements) were informed by evidence-based practice. Scoping review findings highlight health program responses are fragmented and inconsistent and there were no specific programs or models which could be easily utilised to inform the pilot model implementation. Therefore, it was essential to develop a program approach based on a diverse range of evidence. The evaluation findings become much needed practice-based evidence and provide a sound foundation to further develop tools, approaches and measures which allow for monitoring and continuous quality improvement in practice in health care settings. Through the evaluation of the program there are a range of key practice findings which are of importance and warrant further understandings, these included ways of working, clinical approaches, system considerations and workforce.

## Ways of Working / Guiding Principles

Applied principles and ways of working are often under-represented in evidence relating practice models and approaches, however it is necessary to contribute towards both theoretical and applied understandings of the 'right way' of working. The approaches and principles of the Cultural Pathways Program can be implemented in Aboriginal and Torres Strait Islander social and emotional wellbeing responses more broadly. Ways of working describe the importance of working in partnership, getting to know people, and 'meeting people where they are' which considers the unique context of each person (Wilson et al. 2020). The approaches piloted within the program and outlined throughout Chapter Five are summarised in Figure 6.1.

Figure 6.1: Cultural Pathways Program Ways of Working



The approaches implemented in the Cultural Pathways Program were underpinned by reflective practice and reflexivity which are critical for allowing evidence based strategies to emerge (Wilson et al. 2020). Dudgeon, Milroy and Walker (2014) explicitly detail key guiding principles for Aboriginal and Torres Strait Islander social and emotional wellbeing drawn from Swan and Raphael (1995). These include a focus on strengths, holistic health, self-determination, recognition of trauma, racism and the central role of family, kinship and reciprocal relationships. Dudgeon et al. (2014) found that those programs, services and practices which adhered to these guiding principles were the most effective in supporting social and emotional wellbeing. Wilson et al. (2020) outlined a framework for practice in Aboriginal health describing the key strategies implemented in practice by Aboriginal Health Workers and Allied Health professionals including: Aboriginal and Torres Strait Islander and non-Indigenous people working with Aboriginal and Torres Strait Islander health workers building relationships, relinquishing control, an awareness of history, communication, commitment, flexibility (Wilson et al. 2020). An increased focus on ways of working supports working respectfully with Aboriginal and Torres Strait Islander people.

Box 6.2: Practice Recommendation 2, implement strengths-based principles

Recommend the implementation of strengths-based principles in practice and evaluation/articulation to further strengthen evidence-based ways of working.

# Clinical Approaches

The significant experiences of unmet need as highlighted in Study 1 have the potential to inform clinical practice through establishing an evidence-based foundation of the context and needs of communities. By describing these needs community can plan and advocate for responses, consistent with the philosophy of the SA Aboriginal Landscapes Project (see Chapter Three) this study was situated, to empower community ownership and decision making over data. Additionally, policy makers and service have access to data for developing policy and clinical practice approaches which are targeted at addressing those needs. Strategies to promote mental health must also involve holistic approaches which include addressing the social determinants of health (Calma, Dudgeon & Bray 2017; Markwick et al. 2015). Through exploration of the social determinants of health and mental health, this study highlighted high mental health hospitalisation rates, potentially indicating that existing care is not meeting the communities needs for mental health care and treatment (Dudgeon, Boe & Walker 2020). Additionally, there are significant burdens of education, employment, housing, income requiring responses which are able to address these unmet needs. Lastly, this study highlights the importance of access to and utilisation of culturally relevant data to inform mental health care service delivery and planning for Aboriginal and Torres Strait Islander communities.

Cultural Pathways Program evaluation findings re-iterated many of the key findings from Study 1, in particular the complex and interconnected needs of participants and the unmet mental health needs. The programs' culturally developed screening process identified that participants experience on average of 8.4 unmet needs across 14 social and cultural domains, of these the highest proportions were seen in mental health, family and community connection and health needs. In practice this complexity was further highlighted through the implementation of the broker and connect model. While the model was effective at responding pressing and immediate needs, it became evident that the relationship which is often needed to work through multiple needs over a long period of time, including to address mental health needs, was often not achieved by the program or the Facilitators. The depth of the relationship was observed throughout implementation (reflective practice) and in the evaluation yarns (semi-structured interviews) with participants. Whilst participants positively described the relationship with Facilitators and support from the program, it was not evident in most instances that this therapeutic relationship had occurred. There may be many possible explanations for what was

observed, and the program did not specifically evaluate this phenomenon as it was an emergent theme, however the mental health content analysis in Study 3 highlighted that more specific approaches are needed for addressing mental health 'right ways'.

The mental health content analysis pointed towards access to services and developing a primary relationship with a person and/or service to enable service responses to address multiple interconnected needs of participants without needing to make referrals externally for each need (e.g. mental health, financial counselling, food relief, health care). Through the establishment and implementation of this program of work, it became increasingly evident that current practice approaches to social and emotional wellbeing have been reactive to meet the needs of community, and that services have implemented a 'do whatever it takes' approach to the social determinants of health (Pearson et al. 2020). The increasing recognition of Aboriginal and Torres Strait Islander holistic health resulted in service providers across the Country, particularly Aboriginal Primary Care and Aboriginal Community Controlled Health Organisations (ACCHOs), responding to those needs through the creation of social and emotional wellbeing teams to respond to holistic needs. The available evidence to inform this work is severely lacking and these services are often delivered differently depending on the setting, resources, and context. As a result of this, there are no systematic or coordinated clinical practice approaches for social and emotional wellbeing and for addressing the impacts of the social determinants of health. The broker and connect model and other program elements, allowed for a range of needs to be met which otherwise would not, providing a much-needed starting point to consider priority actions required within the service delivery context.

Box 6.3: Practice Recommendation 3, develop and implement therapeutic clinical approaches

Recommend the development and implementation of therapeutic approaches and 'one stop shop' or 'service hubs' to reduce the complexity of clinical practice and streamline the ability to develop meaningful connections/relationships between clinicians/services and clients.

# System Challenges

Complexity was also observed at the systems level in each of the studies, highlighting a range of insights and recommendations. As previously stated, Study 1 findings illuminated unmet needs across all social determinant of health domains including education, employment, housing and income. Scoping review results described a range of service provision contexts and professions which address the social determinants of health and instances of multi-disciplinary approaches within services, however it was not evident from the findings that inter-sectorial approaches or partnerships currently exist. In implementing the Cultural Pathways Program Facilitators were prepared to support participants in various regions by undertaking extensive service mapping, implementing an approach to connect with services and developing partnerships for brokering connections. Program data indicated extensive activity undertaken by Facilitators with other service providers as part of brokering connections to services with diverse stakeholders across the health and social sectors and across the State.

Approaches to policy, funding and service delivery are well known to operate in 'silos' and often there will be a different service provider addressing each domain or unmet need (Carey & Crammond 2015; Carey, Crammond & Keast 2014). From a practice perspective, people can be engaging with a different service provider for each of their needs and each of those providers with each other, in addition to the potential for multiple service providers being required to address one need. If we were to consider an example of one need, such as mental health, a client could have a mental health worker, a counsellor, a mental health program they attend, a General Practitioner (GP) for their mental health plan and each of these may be accessed through a different provider. Complexity often results from interactions among many parts within or between systems (Hawe 2015). Adaptive system thinking encourages multi-level measures which are able to assess the whole system as a result of newly introduced programs or practice (Hawe, Bond & Butler 2009), the pilot nature of this program in a research setting was not intended to achieve this, however, the far-reaching system considerations and complexity continued to emerge.

A complex system is adaptive, includes or connects with other complex systems, and behaves in a non-linear fashion (Hawe 2015; Shiell, Hawe & Gold 2008). Complex systems include primary health care, hospitals, and other service provision environments, where a systems approach needs to consider the impact of making changes to that system

and any interactions within and between an intervention and the context (Shiell, Hawe & Gold 2008). An indicator of system level change is shifts of key 'actors' within the structures that make up the complex system, and with it changes in their relationships with other actors and agencies (Shiell, Hawe & Gold 2008). Relational data can capture these system level effects or changes, this is data collected at the individual level but analysed at the network level using social network methods (Shiell, Hawe & Gold 2008). Relational understandings of the 'social and emotional wellbeing system' or network, such as how service providers work together in a 'real world' system are needed.

Evidence indicates that strong partnerships between service providers can create opportunities for these services to work effectively together, and to maximise time and resources for the best outcomes (Corbin, Jones & Barry 2018). However, it is not well understood how partnerships are enacted in practice to improve social and emotional wellbeing. There is a need to understand partnerships and address complex system challenges to further inform practice which is able to address unmet social and cultural needs. Complex systems thinking also needs to be applied to the policy making process, strong partnerships and referral networks are band-aid solutions to broader systemic issues which can only be resolved through policy reform and evidence-based policy approaches. Evidence aiming to understand policy maker perspectives on the social determinants of health found that they described being able to 'make little progress in advancing comprehensive policies to address social determinants of health' (Baum, Laris, et al. 2013).

Despite understanding the need for action, the complexity of the social determinants of health and health service delivery significantly impact on policy making in relation to the social determinants of health (Baum, Laris, et al. 2013; Carey & Crammond 2015; Carey, Crammond & Keast 2014). Future activities aimed at addressing the social determinants of health must be multi-layered and underpinned by complex systems thinking which can influence individual (micro), organisations and service providers (meso) and the health and social service system (macro).

Recommend understanding of system relationships to reduce complexity and maximise potential for streamlined partnerships in responding to social and emotional wellbeing needs.

Box 6.5: Practice Recommendation 5, policy and advocacy for system challenges

Consider approaches which include policy advocacy to address multi-layered system complexity.

# Workforce Support

The Cultural Pathways Program included a small workforce, and therefore only generalisations can be made about workforce. However, the approach was informed by both practice experience and existing evidence enabling implementation into any context. As part of implementation, a range of gaps and needs were identified both in supporting the programs workforce and through engaging with workforce across other services and sectors. The program evaluation highlighted further consideration is needed for practicebased evidence in relation to workforce support. Aboriginal and Torres Strait Islander health workers experience unique complexities as members of the community who also provide services to their own communities. Aboriginal and Torres Strait Islander workers are not exempt from the lived experiences of the population more broadly including the inequities experienced and the ongoing impact these have on health and wellbeing, yet they are tasked with supporting their communities to navigate and alleviate these challenges (Dickson 2020; Eades et al. 2021; Kirkham, Hoon, et al. 2018; Kirkham, Rumbold, et al. 2018). They work in systems that constantly change or undertake reform which does not always align with cultural values and obligations (Freeman et al. 2017). Aboriginal and Torres Strait Islander people must balance the obligations they have to their community who are often experiencing significant unmet health and social needs and the obligations and expectations of their roles (Kirkham, Hoon, et al. 2018; Kirkham, Rumbold, et al. 2018). These factors leave Aboriginal and Torres Strait Islander workers more likely to be affected by stress and burnout, which in turn impacts on service delivery and community outcomes (Deroy & Schütze 2019; Dickson 2020).

The nature of being an Aboriginal and Torres Strait Islander person in Australia means that there is constant exposure to cumulative traumas including racism, grief and loss, and disadvantage (Barta 2008; Eades et al. 2021; Kelaher, Ferdinand & Paradies 2014; Ketheesan et al. 2020; Larson et al. 2007). Vicarious trauma describes the 'cumulative transformative effect upon the trauma therapist of working with survivors of traumatic events". There is considered to be a natural consequence of caring in which a person upon hearing or witnessing traumatic experiences, can become affected by them (Devilly, Wright & Varker 2009). Burnout is described as a "psychological syndrome in response to chronic interpersonal stressors on the job" (Devilly, Wright & Varker 2009). While little evidence exists on understandings of burnout and vicarious trauma specifically in the context for Aboriginal and Torres Strait Islander communities the relational nature of the community means that stressful experiences are often deeply felt and experienced collectively (Eades et al. 2021). Eades et al. (2021) describes these experiences in the context of research and bearing witness to or collecting qualitative data as having "a triggering impact on the Aboriginal team member for whom these realities were familiar." These daily occurrences and the challenges that they bring contribute to enormous stress for both Aboriginal and Torres Strait Islander consumers and health workers.

The health system relies on the relationships that Aboriginal and Torres Strait Islander workers have with community to provide culturally responsive services, yet these systems and structures fail to recognise or support what is involved in doing this and the cost that it may have on worker wellbeing (Kirkham, Hoon, et al. 2018; Kirkham, Rumbold, et al. 2018). Emerging evidence on the importance of the support and retention of the Aboriginal and Torres Strait Islander workforce continues to highlight a range of strategies and approaches including cultural safety, cultural awareness, leadership, peer support and networks, supervision, self-care and professional development (Aboriginal Health Council of South Australia (AHCSA) 2020; Deroy & Schütze 2019, 2021).

Despite recognising the importance of wellbeing and retention of the Aboriginal and Torres Strait Islander workforce and the role of supervision in achieving that (Deroy &

Schütze 2021; Kirkham, Rumbold, et al. 2018; Oates & Malthouse 2021), there remains an absence of evidence based applied approaches. It is critical the evidence on best practice for workforce support is further developed and implemented to ensure a strong and healthy workforce empowered to support Aboriginal and Torres Strait Islander communities with their social and emotional wellbeing needs.

Box 6.6: Practice Recommendation 6, workforce healing models

To expand and implement the workforce healing model in a 'real-world' clinical setting to support Aboriginal and Torres Strait Islander workforce and evidence which will enable the further development of workforce wellbeing and support models.

*Impact, quality improvement and knowing if it works* 

There are many considerations, challenges and limitations of data which is currently available to describe the needs and measure improvements in social and emotional wellbeing and the social determinants of health. Study 1 highlighted a need for stronger data collection and measures at the individual level to understand the impact of the social determinants of health on mental health (and other health outcomes), to better inform and target action in practice. It is difficult to ascertain a true and accurate understanding of needs and to measure changes over time due to the unreliability of Census and administrative data and a lack of culturally developed and relevant measures. It is essential to understand the social determinants of health more accurately at the community and individual level. Study 1 highlighted the need for mental health outcome measures, beyond hospitalisations, to reflect Aboriginal and Torres Strait Islander definitions and understandings of health. Scoping review findings also illuminated a significant gap in relation measures, with only three programs reporting any sort of measure for the social determinants of health. Of these three programs, two of the programs did not have outcome measures but rather collected pre/post baseline data on demographic information, education and social indicators. Additionally, there were no

clear tools (how to do it) or measures (did it work) described in any of the programs. This significantly impacted on the availability of any data to tell the story of 'what works'. It was also highlighted that while there may be more action being undertaken in practice, it is difficult to measure or learn from this without high quality evaluation which is published or made publicly available (Osborne, Baum & Brown 2013).

The Scoping Review findings highlighted the need for a broader understanding of the characteristics of health programs addressing the social determinants of health including factors such as the financial investment, cost, measures and outcomes. For example, economic considerations were not available in any publicly available information for any programs, however as part of the Indigenous Advancement Strategy Evaluation Framework (Commonwealth of Australia 2018b) the Department of Prime Minister and Cabinet made a commitment to improve transparency to support the knowledge transfer and use of evaluations (Kelaher et al. 2018). Transparency about the investment and cost of program delivery, process and outcomes is important for evidence based practice and the ability to implement strategies that work across multiple settings and jurisdictions (McCalman et al. 2012).

Findings from the Scoping Review in Chapter Two heavily influenced the development of the Cultural Pathways Program approach to address the evidence gaps which were identified in relation to data collection and monitoring. These included consideration of data and measures which align with Indigenous ways of knowing, being and doing, strengths-based approaches and social and emotional wellbeing more broadly. Through this program of work a range of relevant process and activity indicators were developed with data available for dates, times, duration, contact types, and whether any indicators were met.

As identified in 5.2, health record systems do not routinely document the level of activity undertaken to respond to social and emotional wellbeing / social determinants of health. Existing practice approaches vary significantly across contexts and practice-based evidence on how to collect this data is scarce (Bailie et al. 2019; Langham et al. 2017). From a practice and service-delivery perspective this lack of data collection creates challenges for ongoing quality improvement. It is difficult to understand the impact without measuring the inputs, additionally without understanding the extent of activities

undertaken in practice it is difficult to advocate for adequate resources, review outcomes and adjust approaches, workforce and training as required (Bailie et al. 2016).

Box 6.7: Practice Recommendation 6, process and activity measures implemented for social and emotional wellbeing

Recommend process and activity measures are implemented in real-world settings to enable monitoring of activities relating to social and emotional wellbeing.

Box 6.8: Practice Recommendation 7, outcome measures developed and implemented for social and emotional wellbeing

Recommend the development and implementation of culturally relevant outcome measures for social and emotional wellbeing and integrating the ongoing monitoring of these into practice.

# 6.3 Methodological and theoretical considerations

Throughout this thesis Indigenous knowledges have been referenced utilising the well-known ways of knowing, being and doing (Martin-Mirraboopa 2003). The following section will shift this framework towards Being, Knowing and Doing. At the centre of the applied methodological and theoretical approaches of this program of work is Being, and the researcher as an Aboriginal woman; which led to Knowing, conceptualisation and understandings which are grounded in Indigenous knowledges and world views and how non-Indigenous knowledges were utilised and applied, also in alignment with this. Lastly, Doing, through the underpinning of Being and Knowing the researcher in this thesis has applied Indigenous knowledges and methodologies to the research process in ways which contribute to much needed applied approaches to Indigenous methodologies.

#### Being

Ontology (ways of being/how we perceive our reality)

This thesis frames early, the researchers position as an Aboriginal woman and how this is a critical part of the research methodology and has been embedded in the essence of every piece of this research process. Non-Indigenous knowledges understand this is 'insider research' and many disciplines describe reflexivity and reflective approaches as essential for understanding the role of self in our work (Bainbridge et al. 2011; Kanuha 2000; Wilkinson & Kitzinger 2013). The applied use of self throughout this program of work has demonstrated that 'insider' research can be applied to a range of methods and approaches. Through an explicit acknowledgement of insider approaches as a strength to research process can ensure stronger alignment with cultural values and knowledges and keeps Aboriginal and Torres Strait Islander researchers accountable to our communities. Research on the inside has enabled understandings and perspectives which are empowering and focus on strengths of culture and community. The insider approach has allowed for a close relationship to the research and as the findings emerge to inform an iterative, action research design which ultimately benefits communities and avoids contributing to narratives which have been used to control and disempower Aboriginal and Torres Strait Islander people in the past (Archibald et al. 2019; Bainbridge et al. 2011). Indigenous scholars globally increasingly describe Indigenous methodologies or decolonising methodologies which centre Indigenous ways of knowing, being and doing,

returning to our own knowledge systems and frameworks (Archibald et al. 2019). Methodology scholars continue to articulate principles of Indigenous methodologies, however, examples of how these are applied in practice are harder to come by. As Aboriginal and Torres Strait Islander researchers we must *be* who we are, and by doing this explicitly as part of our research methodology brings immense strength to the research we engage in for the benefit of our communities.

#### Knowing

Epistemology (ways of knowing / how we think about it)

A range of Indigenous and non-Indigenous theoretical frameworks underpinned this research, and consistent with the Indigenous methodology, theoretical approaches utilised in this research aligned with telling out stories, our way by focusing on strengths-based approaches and narratives. To enable this approach understandings of data sovereignty and self-determination were at the centre. There is a common assumption that numbers are neutral and thus quantitative research is objective, however, statistics are of human creation, viewed through a lens which is often that of the social, racial and cultural standpoint of their creators (Walter & Suina 2019). In their creation, they then assume the qualities of their makers, in a colonial context this is often that of dominant settler society perpetuating a discourse of stories told about Indigenous communities, used to rationalise dispossession, marginalisation and to exert control over communities (Walter & Suina 2019). This program of work applied Indigenous data protocols and governance which were embedded through Indigenous research methodologies and Indigenous data sovereignty to contribute to higher quality data which can be used by communities (Walter & Suina 2019).

There are many approaches to the collection and analysis of research data in public health, with most critiques levelled at deficit discourses which continue to measure 'gaps' between non-Indigenous and Aboriginal and Torres Strait Islander people (Askew et al. 2020; Walter 2018). Emerging approaches are striving to develop large scale data which is more culturally aligned. One such example is Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing. Mayi Kawayu is a national longitudinal study which through extensive community consultation, includes items on 'cultural practice and expression, sociodemographic factors, health and wellbeing, health

behaviours, experiences and environments, and family support and connection' (Jones et al. 2018). This is one example of promising public health research which is increasingly utilising Indigenous methodologies, and the insights of this thesis further contribute to applied understandings of community driven place-based understandings to understand needs and empower community driven responses.

Program evaluation has great potential to facilitate understandings of practice approaches which work, however many health and social programs are not evaluated (Williams 2018). For Aboriginal and Torres Strait Islander communities evaluation is often perceived negatively due to harms which have been caused in the past (Williams 2018). This can be mediated through Indigenous methodologies which include leadership from Aboriginal and Torres Strait Islander people in evaluation research and more community involvement in interpreting program successes through culturally relevant lenses which take account of cultural, historical, social and economic contexts (Williams 2018). Whilst there are few specifically developed Aboriginal and Torres Strait Islander evaluation frameworks, existing evidence highlights evaluation is best when carried out by those who understand the culture and context, is flexible yet specific to the lives of Aboriginal and Torres Strait Islander people (Williams 2018). Recognising these factors, the evaluation approach was selected purposely for its ability to align with Indigenous knowledges including governance and evaluation approaches which embed Indigenous knowledges and ways of working.

Developmental evaluation supported innovation and adaptation aligning with participatory approaches (Fagen et al. 2011; Gamble 2008; Patton 2010). A range of designs, tools and inquiry frameworks were used at different stages and depending on the needs of the innovation and questions to be addressed (Patton 2010). In addition to the cultural applicability of the method, it was also suitable for foundational understandings required for the social determinants of health. Evaluation continues to draw focus for its important role in Aboriginal and Torres Strait Islander health and wellbeing (Blignault & Williams 2017; Commonwealth of Australia 2018b; Hudson 2016; Williams 2018). Clearly articulated principles, methodological approaches, tools, and methods make important contributions to Aboriginal and Torres Strait Islander evaluation contexts (Williams 2018). The underpinning theoretical approaches and the integration of Indigenous knowledges in this work facilitated culturally safe and responsive *doing* (research practices and approaches).

# Doing

Axiology (values and beliefs/ways of doing)

Through Indigenous ways of being and knowing, a range of applied actions or ways of doing were undertaken to generate culturally relevant understandings. The over-arching strengths-based framing woven throughout the entire of program of work had specific relevance for Study 1 which implemented strengths-based approaches to descriptive epidemiology. This was applied through the operationalisation of variables, methods, selection of data collections to analyse and the decision to avoid the tendency with big data to draw conclusions using deficit items (Walter & Suina 2019). The researcher explicitly set out to avoid deficit-based analysis, which was comparative to non-Indigenous populations, this is challenging when working with the social determinants of health and mental health data, which are innately very deficit-based in the evidence. The tendency to compare Indigenous and non-Indigenous populations to describe health and social outcomes has been a product of dominant cultural research 'about' the Indigenous problem (Walter 2018). In doing this it immediately sets a comparison, a 'standard' for and by which Aboriginal and Torres Strait Islander communities are compared (Walter 2018). Whilst it is unacceptable that there are health and social outcomes that Aboriginal and Torres Strait Islander people do not experience 'parity' with non-Indigenous populations, the need to compare and benchmark against measures which have not been culturally defined or developed does not empower communities or contribute to their sovereignty (Walter 2018). This strengths-based approach was implemented throughout every aspect of this program of work.

Aboriginal and Torres Strait Islander communities can and should have choice in the data that is collected about us, its purpose, and the stories data ultimately tell and who those stories are for. Our data should empower us to understand our own needs, to enact solutions to those needs ourselves, develop our own measures and markers for success and serve as accountability to health and social systems to achieve those solutions (Walter 2018). As a starting point for such an approach, this program of work through the active Indigenous methodological approach centres the community, their needs and goals. The analysis was not descriptive for the sake of describing something but with purpose to understand unmet needs within the context of broader project to do something about it. Through established governance of the Landscape Project which commits to the sovereignty and control of community over data, this was a sound fit for this approach.

The Scoping Review methodological enhancement as described in 4.1 makes a significant contribution to how existing frameworks can better integrate Indigenous ways of knowing. Scoping Review methods provide a structure for evidence synthesis and storytelling while flexible enough to integrate Indigenous knowledges and the cultural appraisal of evidence helps to strengthen culturally relevant understandings whilst also striving to increase the 'value' of Indigenous ways of knowing, being and doing in peerreviewed and grey literature. A critical approach to this study was the involvement and contribution of the Advisory Group which included flexible engagement. The South Australian Aboriginal Health Research Accord (South Australian Health and Medical Research Institute 2014) provided a framework and understandings of how to apply the Accord principles in practice. The alignment and enhancement of the scoping review with Indigenous knowledges supported culturally appropriate story telling in the form of evidence synthesis to establish what we already know (from the evidence) and what we need to better understand, supporting action-based research based on community needs, priorities and understandings. Through presenting this approach at conferences, the researcher has been approached regularly to share the method and insights and there has been significant interest from both Aboriginal and Torres Strait Islander and non-Indigenous researchers in applying the methodology.

The evaluation was underpinned by Aboriginal and Torres Strait Islander knowledges in the research team and through an Advisory Group to develop the program approach and inform research activities. For example, the development of interview questions for semi-structured yarning interviews in the evaluation were iteratively developed with the Advisory Group based on both the emerging findings from the developmental evaluation and the expertise and lived experience from the group on ensuring the most relevant understandings from the qualitative component. Additionally, the Advisory Group were critical in understandings of descriptive information and the story emerging from the data to align with Aboriginal and Torres Strait Islander lived experience. The developmental evaluation was consistent with other evaluation methods and addressed questions to understand and describe the situation (What? Why? When? Where? Who?) and to define through analysis and interpretation focus on action (What? So What? Now What?) (Patton 2010). The approach enabled the evaluator as part of the team, as an insider, iteratively exploring evaluation questions, examining, and tracking implications of adaptions with real time feedback (Patton 2010). This method also allowed for developments and

adaptations to be tracked using a reflective cycle which was innately relational and flexible to respond to complexity, aligning with Indigenous ways of being as described above (Bailie et al. 2020). The actions described throughout this section make a critical contribution to Indigenous methodological applied approaches to enable the growth and development of Indigenous methodologies and methods locally and globally.

# 6.4 Future Research and Knowledge Translation

Knowledge translation has been a significant part of this program of work throughout implementation and transitioning to a focus based solely on knowledge translation on completion. The key knowledge translation activities which are directly informing future research priorities include the implementation of findings directly into the 'real world system' and a range of activities in relation to improving mental health. To conclude this section, areas which have been identified for future research will also be highlighted.

#### System Implementation

A range of knowledge translation activities have been undertaken with a large focus on how to implement these approaches and findings into real world settings for the greatest impact. A key implementation project emerging from this has been with the "Intervening on social and health services' practice to address social determinants of Aboriginal social and emotional wellbeing: Taingiwilta Pirku Kawantila<sup>7</sup> (Strong Community in the North) a 5-year research program undertaken on Kaurna Country. This National Health and Medical Research (NHMRC 1165364) project (Northern Pathways project) aims to strengthen health and social services' responses to address unmet social needs and promote social and emotional wellbeing.

Indigenous methodologies are applied in the co-design, implementation, and evaluation. Aboriginal and Torres Strait Islander leaders oversee the project and an Aboriginal Governance Panel guides the research processes and knowledge translation (Dawson et al. Under Review). The study provides an opportunity to build practice-based evidence on inter-sectorial systems coordination to address unmet social, cultural and health needs through adapted ways of working.

# The study has three objectives:

- 1. To co-design adapted ways of working that strengthen health and social service system responses to the needs of Aboriginal and Torres Strait Islander peoples;
- 2. To implement the adapted ways of working within community settings and health and social service settings through discrete implementation projects;

<sup>&</sup>lt;sup>7</sup> Taingiwilta Pirku Kawantila is the project name given by Kaurna language and knowledge holders - Kaurna Warra Karrpanthi - meaning 'Strong Community in the North'

To developmentally evaluate the co-design, implementation, and impact of these
adapted ways of working on Aboriginal and Torres Strait Islander peoples'
wellbeing and multidimensional practitioner-, service-, and systems-level
outcomes.

In the early stages of the project development the researcher (TB) presented findings to the Aboriginal Governance Panel and Investigators Group and now as part the research team, contributes to project activities and the implementation of findings from this program of work into the ongoing implementation of Taingawilta Pirku Kawantila.

Taingawilta Pirku Kawantila is set on Kaurna Country in the northern region of Adelaide, South Australia. This region has long been experiencing significant social complexities and is rated in the highest quartile of the Australian Bureau of Statistics' Index of Relative Socioeconomic Disadvantage (Australian Bureau of Statistics 2016b). In 2016, 23.7% of South Australia's Aboriginal and Torres Strait Islander population resided in this catchment (n=9,837) (Pearson 2017). The region is served by the Northern Adelaide Local Health Network (NALHN). Northern Adelaide Local Health Network (NALHN) provides hospital, community and home-based services across multiple sites in the northern and north-eastern Adelaide region (SA Health 2023b). Another key translation activity for this program of work has been through the Research Director, Northern Adelaide Local Health Network (NALHN). This study aimed to develop and validate a social determinants of health screening tool, as part of the development and validation, the instrument was piloted with a group of expert stakeholders. The researcher was invited to participate and contribute valuable insights from the Cultural Pathways Program and whilst this tool is not specific to Aboriginal and Torres Strait Islander populations, many of the insights were relevant for the broader population and context for which this study is situated. The output of the NALHN study is a questionnaire to measure social determinants of health that has been developed and validated through qualitative methods. The questionnaire will be field-tested among a large sample of hospital patients in SA (Poirier et al. 2022).

Upon publishing the paper in Chapter 5.1, the researcher was approached by several stakeholders working within the health system to discuss the program. There was a considerable amount of interest from the sector for the structure that could be provided to strengthen the approaches they already undertake. This included an invited presentation

to Central Adelaide Local Health Network (CALHN) Social Work Team in July 2022. Following this and several meetings with the Social Work Director and Senior Managers, Central Adelaide Local Health Network (CALHN) to discuss potential for implementing within their context. The social work team is made up of over 70+ Allied Health professionals who deliver social work services across three hospitals including South Australia's largest public hospital, the Royal Adelaide Hospital. They also cover mental health services and Glenside, State-wide Rehabilitation Services and a range of specialised community and clinical health services across Adelaide (SA Health 2023a). Activities are underway to implement a pilot of the screening tool with the Social Work Team at the Royal Adelaide Hospital who work with renal patients. Whilst this is a small implementation project there is potential for this to expand in time to other teams, and potentially other hospitals and community settings to have significant impact. These key knowledge translation examples highlight an 'appetite' from health and social services for strengthened approaches which have been implemented in the Cultural Pathways Program. Further translation activities are planned with a manuscript in preparation to outline the evaluation findings with a focus on the screening approaches and screening tool for social and emotional wellbeing with plans to enhance the reach of the findings and potential for greater translation into practice.

#### Mental Health Approaches

There are a range of approaches to mental health care in Australia including access to general practitioners, psychiatrists and psychologists which can be accessed in public and private hospitals, community mental health and residential services. Existing approaches to mental health care for Aboriginal and Torres Strait Islander peoples are inadequate with a significant lack of understanding of stressors specific to Aboriginal and Torres Strait Islander communities (Calma, Dudgeon & Bray 2017; Dudgeon et al. 2016; Haswell-Elkins et al. 2007). Current approaches are inadequate in responding to the ongoing impacts of colonisation, including cultural loss, racism, inter-generational and cumulative impacts of colonial violence, dispossession, extreme poverty and disadvantage from social exclusion (Calma, Dudgeon & Bray 2017; Dudgeon et al. 2016; Haswell-Elkins et al. 2005). Further, the primary role of social and emotional wellbeing and its relationship to mental health is not well understood. There are very few Aboriginal and Torres Strait Islander psychologists and psychiatrists and not enough wellbeing workers in Primary Health Care and Aboriginal Community Controlled Health Services to respond to the significant demand for mental health and wellbeing services and supports (Calma, Dudgeon & Bray 2017; Dudgeon et al. 2016). There is a pressing need for sound cultural and clinical practices which are self-determined by Aboriginal and Torres Strait Islander communities. Further, services need to be culturally safe and informed by cultural understandings for providing clinical care including assessment and case management for mental health (Calma, Dudgeon & Bray 2017; Dudgeon et al. 2016).

In 2020, Gayaa Dhuwi (Proud Spirit) Australia was established as the Aboriginal and Torres Strait Islander (Indigenous) social and emotional wellbeing, mental health and suicide prevention national leadership body. Gayaa Dhuwi is governed and controlled by Indigenous experts and peak bodies and promotes collective excellence in mental health care (Gayaa Dhuwi (Proud Spirit) Australia 2023). The Gayaa Dhuwi (Proud Spirit) declaration has five themes which calls for a focus on Aboriginal and Torres Strait Islander concepts of social and emotional wellbeing and that mental health and healing need to be recognised across all parts of the Australian mental health system. The declaration argues that through the combined cultural and clinical knowledges the greatest contribution can be made to mental health and wellbeing outcomes and that measures should also be consistent with cultural values and clinical outcomes (Dudgeon et al. 2016)

Despite being identified as a key priority in the *Next Steps for Aboriginal Health Research: Exploring how research can improve the health and wellbeing of Aboriginal people in South Australia* (King & Brown 2015), South Australian Aboriginal mental health and social and emotional wellbeing research is significantly lacking. Through the partnerships developed by the researcher, and the foundational understandings in this PhD a program of work will be developed to focus on this priority. The researcher has developed a range of strategic partnerships, including the Office for the Chief Psychiatrist (SA Health), who will be developing the first Aboriginal mental health and wellbeing centre in South Australia. This work and the skills I have learnt will translate into a project which aims to identify service provision approaches and needs for Aboriginal and Torres Strait Islander social and emotional wellbeing and mental health in South Australia. The objectives of this study are to::

- Develop an environmental scan tool ('the survey') to identify and summarise current service delivery approaches, models of care, and identify needs and priorities about social and emotional wellbeing and mental health services in South Australia;
- Engage key stakeholders for the implementation of the survey to Aboriginal and Torres Strait Islander social and emotional wellbeing and mental health providers;
   and
- 3. Analyse survey results and rapidly translate findings to inform the community and stakeholder consultations and more broadly the development of the SA Aboriginal Mental Health and Wellbeing Centre.

This project will be implemented as part of the developing partnership between the Office for the Chief Psychiatrist (SA Health) and Wardliparingga. This partnership aims to establish a strong evidence-based underpinning for the bi-lateral agreement to develop an Aboriginal Mental Health and Wellbeing Centre in South Australia (the 'Wellbeing Centre'). This project is a foundational piece of work and is pragmatic for timely completion with the available resources and timeframe. The intention for this project is to contribute rapid translation of findings to inform the Aboriginal Mental Health and Wellbeing Centre targeted consultations with stakeholders and community.

This research as a foundational piece of work has identified key research needs and priorities to build into continuing action. A commitment to increased publishing of

applied methodology will enable the growth of Indigenous methodologies. Further research by Indigenous researchers underpinned by Indigenous ways of knowing, being and doing will strengthen the evidence-base for practice in social and emotional wellbeing and mental health. There is a pressing need for future research to focus on mental health needs, responses and models of care which align with social and emotional wellbeing and holistic health. This research should consider system context and challenges beyond individual responses. Lastly, future research must have a focus on impact and outcomes, not just describing problems but an ability to know if by intervening there is a change in social and emotional wellbeing outcomes, including physical health measures and other culturally relevant outcomes.

#### 6.5 Conclusion

There is a long and complex history which has shaped and continues to influence the contemporary lived experiences of Aboriginal and Torres Strait Islander communities. Bringing together an understanding of history, while focusing on the strengths, resources, and resilience of communities, can enable Aboriginal and Torres Strait Islander health research and evidence-based responses which are self-determined, culturally safe, and relevant. This thesis presents a framework for action in practice from social determinants of health conceptualisation and understandings to practice elements for a model of care. This makes a significant contribution to an evidence gap and is intended to inform health system practice for the social determinants of health and social and emotional wellbeing. The Indigenous methodology, articulations of how the methodology has been applied, how methods have been adapted or enhanced, and how this contributes to high quality and culturally responsive and meaningful research provide much needed contributions to Indigenous methodological understandings and applications.

This is research with impact, not only does each stage contribute to needs identified by the community in a meaningful and positive way but the Cultural Pathways Program contributed to brokering connections and influencing the unmet needs and experiences of over 116 individual participants across South Australia. Further, program elements which can be implemented in health systems are being implemented in two settings with the potential to expand these and contribute more broadly to action on the social determinants of health to promote social and emotional wellbeing. Findings of this work identify clear priorities for future research including the need for therapeutic and culturally responsive approaches to both social and emotional wellbeing and mental health care and the need to develop and systematically collect outcome measures which allow understandings the true impact of taking action on the social determinants of health on health and wellbeing outcomes.

This program of work has provided an exceptional, complex, challenging and rewarding training program for me as an Aboriginal researcher to obtain skills in descriptive epidemiology, evidence reviews and synthesis, and program development, implementation, and evaluation utilising both quantitative and qualitative methods. Additionally, I have developed expertise in a breadth of topics from social and emotional wellbeing and mental health, the social determinants of health, data collection, data

sources, measures and limitations, health and social system service delivery, workforce support, and organisational, system and policy considerations. These new skills and knowledge have all been underpinned by Indigenous ways of knowing, being and doing and will contribute significantly to my ability to continue to undertake high quality research with and for communities with meaningful impact and contributing to the health and wellbeing of my community long into the future.

# APPENDIX 2.1: ABORIGINAL HEALTH RESEARCH ETHICS COMMITTEE (AHREC) APPROVAL





#### 5 November 2018

| Principal Researcher (as per the AHREC application form): | Ms Tina Brodie                                  |
|---|---|
| Organisation:   | Wardliparingga Aboriginal Research Unit, SAHMRI |
| Via email to corresponding researchers:                   |   |

RE: Knowledge to Action: addressing the social determinants of Indigenous health to improve

Aboriginal peoples' Social and Emotional Wellbeing

AHREC Protocol #: 04-18-791

Dear Tina,

Thank you for your submission and requesting ethical review from the Aboriginal Health Research Ethics Committee (AHREC).

I am pleased to advise that the study was reviewed and approved by AHREC at its meeting held on 1 November 2018. We wish you well with the studies and look forward to receiving your progress reports. Please be advised that, in accordance with the National Statement, AHREC requires researchers to submit reports for monitoring purposes on an annual basis. Regardless of the approval date, AHREC implements a streamlined annual reporting deadline for all studies and requires researchers to submit their annual reports every November. Please be advised that the first annual report of the study is due by 30 November 2019. Please plan for any subsequent reporting deadlines accordingly.

Please also be advised of the standard conditions of approval below.

If you require further information, please do not hesitate to contact the Executive Officer, Dr Gokhan Ayturk, from

Sincerely yours,

Dr Gokhan Ayturk on behalf of

Amanda Mitchell Chairperson, AHREC

23 July 2020

Dr Gokhan Ayturk Senior Research and Ethics Officer AHCSA

Dear AHREC Chairperson and Members,

## Re: Modification Request for AHREC 04-18-791: Knowledge to Action: addressing the social determinants of health to improve Aboriginal peoples' Social and Emotional Wellbeing

Provided herewithin is a detailed modification request for AHREC 04-18-791 originally approved for Objectives 1 and 2 on 5 November 2018. This modification request relates to Objective 3, which seeks to evaluate the Cultural Pathways Program [AHREC 04-17-733] and determine its effectiveness in meeting social and emotional wellbeing needs of South Australian Aboriginal people. Outlined below are the details of this modification request.

Specifically, Objective 3 includes the following approaches that:

- 3a. Describe the Cultural Pathways Program;
- 3b. Understand and map the interactions between Program Facilitators and Program Participants; and
- 3c. Explore the Facilitator and Participant experiences of the Cultural Pathways Program in meeting Aboriginal social and emotional wellbeing needs.

## 3a) Describe the Cultural Pathways Program and 3b) Understand and map the interactions between Facilitators and Program participants

As part of routine practice the Cultural Pathways Program collects data in relation to participant characteristics (e.g age, sex, location), their identified social and cultural needs (e.g. education, financial literacy) and their engagement with the program and the services connected with (e.g. participant and service connections). In addition, each participant has recorded subjective, objective, assessment plan (SOAP) case notes.

I am requesting access the program dataset for secondary analysis in order to describe the implementation of the program and the interactions between Facilitators and participants. These data will be used to define the subgroups of participant engagement for the qualitative aspect of Objective 3c (detailed below). Participants will only be included if they have previously consented to participate in the research component of the Cultural Pathways Program and data accessed for this study will be de-identified. A descriptive analysis of program indicators will form an aggregated evaluation report, and will be complemented by a narrative synthesis of case notes to provide an enriched understanding on participant engagement and brokerage to social and health services.

As part of routine supervision, reflections from all Program Facilitators have been documented in relation to the delivery and implementation of the program which include practice, program delivery, systems and the broader context. I am requesting access to these reflections as a

data source. These reflections are not specific to any individual person, case or participant and relate broadly to the implementation of the program and practice improvement. Data analysis will include a narrative description of program implementation from the perspective of Facilitators.

Data storage and management will be as per original ethics application, data will be password protected on the SAHMRI server only accessible by the researcher and research team.

## 3c) Explore the Facilitator and participant experiences of the Pathways intervention in meeting Aboriginal social and emotional wellbeing needs.

Facilitator experiences will be explored utilising reflective practice as identified in 3a and 3b above. In order to explore the experiences of participants I am seeking to undertake semi-structured yarning style interviews with participants. The proposed approach is summarised in the Process Flow (Appendix 1) and is detailed as follows:

#### Recruitment

Participants will be selected at random drawing on 3a and 3b for defining gender balanced subgroups and will include 15-25 participants or until saturation is reached. Participants will have consented to engaging in the research process as part of the CPP consent process (AHREC 04-17-733). Participant contact details will be provided to the Primary Researcher, Tina Brodie who will make contact with participants. The primary researcher will explain the purpose of the evaluation as per the recruitment script (Appendix 2) and invite participation in a semi-structured yarning style interview at a time and location convenient to them. Where participants prefer that interviews be conducted in their home, the primary researcher will be accompanied by another researcher. Male participants will be contacted initially by a male Research Assistant to confirm attandance at the interview. The time commitment will depend on the participant with a flexible approach planned to enable connections to services or additional support through up to three 30-90 minute visits (Appendix 1).

#### Information and Consent

Participants will be provided with an information sheet as detailed in Appendix 3 by email/mail and the primary researcher will allow a minimum of three working days for review before contacting participants to obtain consent. Consent will be obtained as per the consent form in Appendix 4 before proceeding to the interview. Participants will be advised that their participation is voluntary and that if they choose not to participate this will in no way impact on their relationship with and receipt of services from the Cultural Pathways Program. Participants will be advised that they can withdraw their consent to participate at any time up until the point of analysis and that their involvement in this project is separate to their involvement in the Cultural Pathways Program and as such requires additional consent.

#### Case Note Review

Once consent is received individual case notes will be reviewed prior to the interview to personalise the yarn to individual circumstances, to support rapport building through a more personalised yarning style and to avoid where possible the strain experienced by individuals when they have to re-tell their stories that can be distressing, an adverse events protocol has been attached in Appendix 7.

#### Yarning / Interview

Interviews will be conducted in a semi-structured yarning style as per the interview guide (Appendix 5) which encourages safety and comfortability for participants. Questions (Appendix 6) have been selected as part of an iterative process which has included reviewing the program protocol, aims and objectives and any themes which have been illuminated throughout the implementation of the program. The questions have been developed in consultation with the Cultural Pathways Program facilitators, research team and an Advisory Group. The Terms of

Reference for the group are attached in Appendix 8. Participants will be supported throughout the yarning process by the primary researcher who is a qualified social worker. Should any adverse events occur or participants become distressed the interview will stop immediately and the distress protocol outlined in Appendix 7 will be implemented to ensure the safety and wellbeing of participants.

#### Follow up yarn if required

If it is identified in the interview process that participants continue to experience unmet needs they will be offered to re-connect with the Cultural Pathways Program or be supported directly by the primary researcher with referrals to appropriate services.

#### Data Analysis

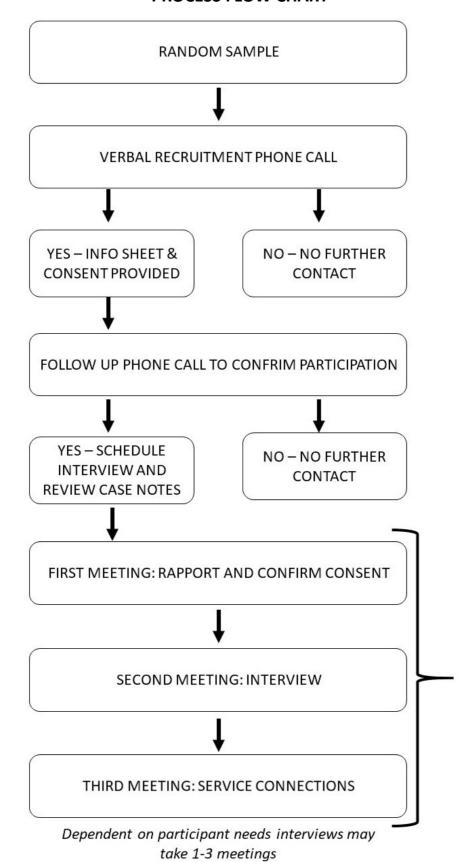
Participants will be provided with a transcription of the recorded interview for their approval before being included in the analysis. Results will be aggregated and overall themes will be reported by subgroups and gender. To support participant confidentiality no identifying data or information will be shared. Data will be stored securely on SAHMRI server as stated in the original application and individual information is part of this PhD project and not the Cultural Pathways Program and therefore will be stored seperately.

Thank you for your consideration of this modification request.

Yours sincerely

Tina Brodie
PhD Candidate
Wardliparingga Aboriginal Health Equity
South Australian Health & Medical Research Institute

## APPENDIX 1 PROCESS FLOW CHART



#### **VERBAL RECRUITMENT SCRIPT**

Hi [participant].

My name is [name of researcher] from Wardliparingga Aboriginal Health Equity at SAHMRI. I am getting in touch with you today as you previously worked with the Cultural Pathways Program and at that time you agreed to be contacted as part of the evaluation of the program. Do you remember working with the Cultural Pathways Program?

If no.

Thank participant for their time and remind them that CPP is available for them should they require any suppoer in the future.

#### If yes:

That's great, we want to yarn to participants about their experiences with the program so that we can learn from them and use what we learn to influence/improve programs for our mob.

There is no obligation to participate but if this is something you would be interested in participating in, all I need as your address or email address – wichever you prefer - to send out more information.

Once you have had time to review the information I would be back in touch to see if you would like to organise a time for us to meet at a time a location that suits you to yarn further.

Are you happy for me to send out further information?

If yes:

Obtain details and thank participant for their time and let them know when they can expect to hear from me.

If no:

Thank participant for their time and remind them that CPP is available for them should they require any suppoer in the future.

#### **Information Sheet for Participants**

#### **Project Title:** Cultural Pathways Program Evaluation

#### INFORMATION SHEET: This Is For You to Keep

**Objectives of this research:** To evaluate the Cultural Pathways program which aims to alleviate stress and worry by increasing access to support services and improve health and wellbeing.

**Who is involved:** The research is being conducted by the Wardliparingga Aboriginal Health Equity Unit at the South Australian Health and Medical Research Institute (SAHMRI). Tina Brodie is the PhD candidate leading this research with supervision from Professor Alex Brown, Dr Odette Pearson and Dr Natasha Howard. This research is informed by [advisory group]

What participation will involve: Participation is entirely voluntary. If you choose not to participate this will not affect your relationship with those involved in this project or the Cultural Pathways Program. Should you be willing to participate, you will be invited to participate in the following activities:

- 1. An initial meeting and refresher of the Cultural Pathways Program;
- 2. Yarning (semi-structured interview) about your experiences with the Cultural Pathways Program; and
- 3. If necessary, an additional meeting to ensure you have everything you need and to connect you with any necessary services and supports.

With permission, yarning as part of the interviews will be digitally recorded and transcribed into written words to be used during analysis. If you would prefer not to be recorded, notes will be taken by the researcher during the session. If you choose to participate in an interview and subsequently wish to withdraw from the study, you may do so at any time by contacting the research team.

#### Information gathered will be used to:

1) inform an evaluation report which describes the experiences of Aboriginal and Torres Strait Islander community members in relation to their engagement with the Cultural Pathway Program; 2) inform the development of a holistic service model that aims to address unmet health and social needs in the Aboriginal community to promote social and emotional wellbeing.

**Reporting of results:** The results will be reported via presentations and published reports. Reported research findings will never identify individual participants.

**Benefits to participants:** There will be no direct benefit to you as a result of participation. Findings from this study will be used to inform the development of services for Aboriginal and Torres Strait Islander community members.

**Potential risks and participant rights:** You may experience distress as a result of discussing challenging experiences. The interviewer as per the distress protocol developed for these interviews can provide immediate support and make any necessary connections to adequate support services if you become distressed. You may choose to stop yarning at any stage and withdraw your consent to participate.

**Confidentiality**: There are stringent processes in place to protect your privacy:

- Any information you provide to us will be de-identified and accessible only by the Research Team
- All quotes from participants used in reporting the results will be de-identified using broad descriptors
- All data will be stored electronically on a password protected server at the South Australian Health and Medical Research Institute in accordance with data management policies
- All data will be stored for a minimum of five years after which it will be deleted from the server including any backup copies on the server
- No third parties will be given access to the data
- The information you provide will only be used for the purposes of the study and no other, without your expressed permission

#### **Ethical Approval:**

This Research Project has been assessed and approved by the *Aboriginal Human Research Ethics Committee* of the *Aboriginal Health Council of South Australia* and the *University of Adelaide's Human Research Ethics Committee*. If you have any concerns or complaints regarding the ethical conduct of the research, please contact the Ethics Officer of the *Aboriginal Human Research Ethics Committee*, Aboriginal Health Council of South Australia: Dr Gokhan Ayturk on

**If you wish to discuss the study in more detail** please contact: Ms Tina Brodie, PhD Candidate, Wardliparingga Aboriginal Health Equity Unit, SAHMRI, on

#### **CONSENT FORM**

#### **Project Title:** Cultural Pathways Program Evaluation

#### Participation is voluntary, this means you can say NO.

- I have received written information about this research project and the study has also been explained to me.
- I fully understand the purpose of the research and my involvement in it. I have had a chance to ask questions and am comfortable with the answers I have been given.
- I understand that I may not directly benefit from taking part in the project.
- I understand that my case records held by the Cultural Pathways Program will be reviewed prior to this interview.
- I understand that this Interview will be digitally recorded with my permission and that the researcher will turn off the tape if I ask them to.
- I understand that if I would prefer not to be recorded, written notes will be taken.
- I understand that only if I choose to participate in an interview, I will have an opportunity to review and edit my comments (which have been transcribed from the audio file into a written document) prior to the researchers' analysis.
- I understand that I may withdraw from the research project at any stage without negative impact from the Cultural Pathways Program.
- If I withdraw from the study, information I have given during an interview will be removed up until the point of analysis.
- I understand that I will retain ownership of all information (intellectual property) that I provide to the study.
- I understand that while information gained during the study may be published, I will not be identified in any way and my personal information will remain confidential.

| Name of participant:             |   |
|----------------------------------|---|
| Signed:                          | Date:   |
| involved                         | ject to the participant and believe that he/she understands what is |
| Researcher's name:               |   |
| Researcher's signature and date: |   |

#### **INTERVIEW GUIDE**

The approach to the interviews is a semi-structured style and to ensure consistencies this interviewer guide will be implemented. Individual case notes will be reviewed prior to the interview to personalise the yarn to individual circumstances, to support rapport building through a more personalised yarning style and to encourage safety and comfortability for participants.

#### Introduction and rapport:

- Thank you for taking the time to yarn with me today
- How are you feeling today? Are you keeping well?
- How have you found this year with all that has been happening...

#### Today we are going to talk about:

- Your experiences with the Cultural Pathways Program
- How you found working with the faciliator
- The changes/impact the program made for you

Before we get started, I wanted to confirm you are okay with me recording our yarn today – if not that's okay I can take some notes as we talk.

I want to make this yarn as easy for you as I can and if at any time you would like to stop or there is something you prefer not to answer or talk about that is completely fine, just let me know, we can stop at any time or we can move on to yarn about something else.

Re-visit their engagement with the program as per the case notes:

- When we first met you in [date] you identified a range of needs, some of the things I can see here are that you were looking for support with [eg housing, transport,]
- I can also see that we worked with you on those things until [date]
- Would you like to go through the screening tool again to see how things are going for you now?

#### Proceed to interview:

I have a few things I am really interested in hearing about from your perspective, are you happy for me to start going through those now?

If yes,

Okay great, so going back to when we worked with you previously, can you tell me more about what was happening for you at the time? [question 1]

Interview would then follow yarning style with opportunity to bring up questions at different points as per Appendix 6, Interview Questions.

For example: I am interested in hearing more about your understanding of the program and if you were to describe this program to a family member, what would you say? [question 2]

If no.

That's completely fine, we have been through a few really important things already today. How about we organise another time for me to come back to yarn further?

#### **INTERVIEW QUESTIONS**

The proposed questions will be used more as a guide or talking points for the interviewer as per the interview guide in Appendix 5. The approach is a yarning style with the interviewer naturally covering off on the key questions and points throughout the semi-strucutred interview. Questions may not flow in a linear order and themes will be picked up throughout the yarn.

| Theme area                           | Question   |  |  |  |  |  |  |  |  |  |
|--------------------------------------|--|--|--|--|--|--|--|--|--|--|
| Addressing social and cultural needs | You identified [identified needs eg housing] and we addressed [needs we addressed] eg connection to Housing SA] can you tell me more about what was happening for [identified need eg housing] at that time? |  |  |  |  |  |  |  |  |  |
|                                      | If you were to describe this program to a family member, what would you say?   |  |  |  |  |  |  |  |  |  |
|                                      | Would you refer someone else in your family or community to this program? If yes, why? If no, why?   |  |  |  |  |  |  |  |  |  |
| Interactions with                    | What did you think of the role of the Facilitator?   |  |  |  |  |  |  |  |  |  |
| Program Facilitator                  | What were the benefits you experienced from seeing the Facilitator?  |  |  |  |  |  |  |  |  |  |
| Strength-based                       | How did the program make you feel?   |  |  |  |  |  |  |  |  |  |
| practice                             | Did working with the Facilitator make you feel more or less supported? In what ways?   |  |  |  |  |  |  |  |  |  |
|                                      | Did working with the Facilitator make you feel more capable? In what ways?   |  |  |  |  |  |  |  |  |  |
|                                      | Did working with the Facilitator help you to see or find any strengths you didn't know you previously had?   |  |  |  |  |  |  |  |  |  |
| Impact (Change)                      | What changes have you noticed since being involved in the program in yourself, or your day to day life?  |  |  |  |  |  |  |  |  |  |
|                                      | Can you describe any differences in your ability to manage the challenges you face day to day, compared to before?   |  |  |  |  |  |  |  |  |  |
|                                      | If you had to, would you be able to do the same thing that you did with the facilitator, by yourself?  |  |  |  |  |  |  |  |  |  |
|                                      | Have you since had any experiences where you have had to seek out and engage services? How has that gone for you?  |  |  |  |  |  |  |  |  |  |

#### DISTRESS PROTOCOL

If a participant indicates they are experiencing a high level of emotional stress, or exhibit behaviours which suggest the participant is distressed (shaking, crying, hyperventilating, etc), these steps will be followed to ensure the safety and wellbeing of the participant.

#### Stage 1 Response

- •Stop the interview
- •Offer immediate support
- •Ask the participant if they are okay

#### Review

- •If the participant feels able to carry on, resume session
- •If the participant is unable to continue, go to stage 2

#### Stage 2 Response

- •Ask the participant if they would like to contact anyone, or if they'd like the Interviewer to on their behalf (family member, friend)
- •If the participant is unable to self-regulate and appears to heighten further, the Interviewer will contact the mental health triage line on **13 14 65**.
- •If the participant begins threatening harm (self or to others), contact appropriate emergency services on 000.

## Follow Up

- •If the participant provides consent, the Interviewer is to contact the participant within 72 hours to check on their well-being.
- •Offer to re-connect the participant with the Cultural Pathways program facilitators.
- Provide the participant with support numbers and make any necessary referrals to support services







ABN 54 141 228 346

P 08 8128 4000 SAHMRI, North Terrace, Adelaide SA 5000 Australia PO Box 11060. Adelaide SA 5001 www.sahmri.com

10 September 2020

Dr Gokhan Ayturk Senior Research and Ethics Officer AHCSA

Dear AHREC Chairperson and Members

Re: Modification Request for AHREC 04-18-791 - Knowledge to Action: addressing the social determinants of health to improve Aboriginal peoples' Social and Emotional Wellbeing

I would like to thank the Aboriginal Health Research Committee (AHREC) for their review of the application entitled "Knowledge to Action: addressing the social determinants of health to improve Aboriginal peoples' Social and Emotional Wellbeing" (04-18-791) on 6 August 2020. Please find detailed the clarifications requested for out of session review.

#### Individual Case Notes

It was not found clear what is meant by 'individual case notes' on page 2 and the Committee could not find an explanation of this on the information sheet or consent form. The statement "each participant has recorded subjective, objective, assessment plan (SOAP) case notes" was also noted. Are these medical records or reflections regarding the Program? Please explain what is meant by 'individual case notes' and what they entail, and ensure that the explanations are reflected on the PIS and consent form.

'Individual case notes' comprise information the Cultural Pathways Program collects as part of the service provided to participants including dates, times and types of contacts, goals identified by participants and any service connections made. A SOAP note entry documents progression, and is required after any interaction with, or for, the participant. Facilitators use SOAP notes to record reflections of the engagament or interaction. SOAP notes describe:

- The type of contact, location, people present, etc.
- Any changes of the issue/s from the last session from the participants perspective.
- Observations of the participant's behaviour during the session.
- An assessment of progress towards participants self-identified priority areas and the
  objectives established in the previous session including any objectives that have been
  met since the previous session.
- Assessment of any themes or patterns within the session and should inform the next steps or 'plans' for future sessions.
- Plans for follow up action including the steps to be taken after the session has ended including any relevant activities or tasks that will need to be made on the part of the Facilitator or participant.

The updated Participant Information Sheet (Appendix 1) and Consent Form (Appendix 2) with the case note components highlighted are attached for your reference.

#### Participant Sub-Groups

On page 2, it was stated that there will be subgroups and recruitment will be gender balanced. The Committee was not clear regarding how the subgroups will be formed and what the inclusion criteria will be, and if there is the potential for participants to be identified depending on what sub-groups are utilised – please explain.

The outcome of of interest for the participant sub-grouping is engagement and the groups will be used to understand the types of experiences for participants across three categories which have been defined with input from the PhD Advisory Group. Grouping of participants will be undertaken by reviewing the level of engagement with the program using the program activity data and program indicators. As described above individual case notes comprise information the program collects as part of providing services to participants. Activity data and program indicators are drawn from these individual case notes. Program indicators are recorded as 'met' when an activity has been undertaken or outcome achieved to meet a participant need (e.g connected to financial counselling, supported to access mental health support etc).

The sample size will include approximately 10 participants (5 female participants and 5 male participants) from each group.

Descriptions of the sub-groups and criteria for inclusion is as follows:

| Engagement  | Partial Engagement   | Limited Engagament   |
|---|--|--|
| Participants progress quickly through actions. When the required indicators are achieved the participant completes the program. | Participants address 1-2 indicators and then advise they do not require further support OR engage less over time ending with the program with some indicators met.             | meeting disengage - which  |
| Inclusion: <5 unsuccessful phone calls 3 or more Indicators met  Exclusion: >6 unsuccessful phone calls <3 Indicators met       | Inclusion: 6 or 7 unsuccessful phone calls 2 Indicators met  Exclusion: 5 or less unsuccessful calls 8 or more unsuccessful calls Less than 2 but greater than 1 indicator met | Inclusion >8 unsuccessful phone calls 1 or less Indicators met  Exclusion <7 unsuccessful phone calls >1 Indicator met |

Confirmation of engagement category will be obtained by reviewing individual case notes to ensure most relevant allocation to a sub-group. Reported findings will be aggregated and individuals will not be identified or identifiable as part of this process. The sub-group approach to the sample is to ensure the inclusion of perspectives of participants from across these groupings.

Please let me know if any further information or clarifications are required.

Yours sincerely

Tina Brodie
PhD Candidate
Wardliparingga Aboriginal Health Equity
South Australian Health & Medical Research Institute

#### **Information Sheet for Participants**

#### **Project Title:** Cultural Pathways Program Evaluation

#### INFORMATION SHEET: This Is For You to Keep

**Objectives of this research:** To evaluate the Cultural Pathways program which aims to alleviate stress and worry by increasing access to support services and improve health and wellbeing.

Who is involved: The research is being conducted by the Wardliparingga Aboriginal Health Equity Unit at the South Australian Health and Medical Research Institute (SAHMRI). Tina Brodie is the PhD candidate leading this research with supervision from Professor Alex Brown, Dr Odette Pearson and Dr Natasha Howard. This research is informed by the Addressing the Social Determinants of Health Advisory Group.

What participation will involve: Participation is entirely voluntary. If you choose not to participate this will not affect your relationship with those involved in this project or the Cultural Pathways Program. Should you be willing to participate, you will be invited to participate in the following activities:

- 1. Review of your participant record from the Cultural Pathways Program which includes the needs you identified previously, and support provided to you by the program;
- 2. An initial meeting and refresher of the Cultural Pathways Program;
- 3. Yarning (semi-structured interview) about your experiences with the Cultural Pathways Program; and
- 4. If necessary, an additional meeting to ensure you have everything you need and to connect you with any necessary services and supports.

With permission, yarning as part of the interviews will be digitally recorded and transcribed into written words to be used during analysis. If you would prefer not to be recorded, notes will be taken by the researcher during the session. If you choose to participate in an interview and subsequently wish to withdraw from the study, you may do so at any time by contacting the research team.

#### Information gathered will be used to:

inform an evaluation report which describes the experiences of Aboriginal and Torres Strait
 Islander community members in relation to their engagement with the Cultural Pathway Program;
 inform the development of a holistic service model that aims to address unmet health and social needs in the Aboriginal community to promote social and emotional wellbeing.

**Reporting of results:** The results will be reported via presentations and published reports. Reported research findings will never identify individual participants.

**Benefits to participants:** There will be no direct benefit to you as a result of participation. Findings from this study will be used to inform the development of services for Aboriginal and Torres Strait Islander community members.

**Potential risks and participant rights:** You may experience distress as a result of discussing challenging experiences. The interviewer as per the distress protocol developed for these interviews can provide immediate support and make any necessary connections to adequate support services if

you become distressed. You may choose to stop yarning at any stage and withdraw your consent to participate.

**Confidentiality**: There are stringent processes in place to protect your privacy:

- Any information you provide to us will be de-identified and accessible only by the Research Team
- All quotes from participants used in reporting the results will be de-identified using broad descriptors
- All data will be stored electronically on a password protected server at the South Australian Health and Medical Research Institute in accordance with data management policies
- All data will be stored for a minimum of five years after which it will be deleted from the server including any backup copies on the server
- No third parties will be given access to the data
- The information you provide will only be used for the purposes of the study and no other, without your expressed permission

#### **Ethical Approval:**

This Research Project has been assessed and approved by the *Aboriginal Human Research Ethics Committee* of the *Aboriginal Health Council of South Australia* and the *University of Adelaide's Human Research Ethics Committee*. If you have any concerns or complaints regarding the ethical conduct of the research, please contact the Ethics Officer of the *Aboriginal Human Research Ethics Committee*, Aboriginal Health Council of South Australia: Dr Gokhan Ayturk on

**If you wish to discuss the study in more detail** please contact: Ms Tina Brodie, PhD Candidate, Wardliparingga Aboriginal Health Equity Unit, SAHMRI, on

#### **CONSENT FORM**

#### **Project Title:** Cultural Pathways Program Evaluation

#### Participation is voluntary, this means you can say NO.

- I have received written information about this research project and the study has also been explained to me.
- I fully understand the purpose of the research and my involvement in it. I have had a chance to ask questions and am comfortable with the answers I have been given.
- I understand that I may not directly benefit from taking part in the project.
- I understand that my participant record held by the Cultural Pathways Program will be reviewed prior to this interview which includes the needs I previously identified and support received by the program.
- I understand that this Interview will be digitally recorded with my permission and that the researcher will turn off the tape if I ask them to.
- I understand that if I would prefer not to be recorded, written notes will be taken.
- I understand that only if I choose to participate in an interview, I will have an opportunity to review and edit my comments (which have been transcribed from the audio file into a written document) prior to the researchers' analysis.
- I understand that I may withdraw from the research project at any stage without negative impact from the Cultural Pathways Program.
- If I withdraw from the study, information I have given during an interview will be removed up until the point of analysis.
- I understand that I will retain ownership of all information (intellectual property) that I provide to the study.
- I understand that while information gained during the study may be published, I will not be identified in any way and my personal information will remain confidential.

| Name of participant:                           |                                  |                                   |
|--|----------------------------------|-----------------------------------|
| Signed:  | Date:                            |                                   |
| I have explained the research projectinvolved. | t to the participant and believe | e that he/she understands what is |
|  |                                  |                                   |
| Researcher's name:                             |                                  |                                   |
| Researcher's signature and date:               |                                  |                                   |

#### **Tina Brodie**

From: Gokhan Ayturk

Sent: Friday, 11 September 2020 9:21 AM

To: Tina Brodie

**Subject:** RE: Modification Request for AHREC 04-18-791

Dear Tina,

RE: Knowledge to Action: Addressing the social determinants of health to improve Aboriginal peoples'

Social and Emotional Wellbeing AHREC Protocol #: 04-18-791

Thank you for submitting the modification request dated 23/7/2020 and seeking ethical review by AHREC, and also responding to the queries raised.

I am pleased to inform you that the response was reviewed out-of-session and met with support, and the proposed changes have been approved.

Please retain a copy of this correspondence for your records and do not hesitate to contact us if you need further information.

Thanks, Gokhan

Kind regards, Dr Gokhan Ayturk

Senior Research and Ethics Coordinator – Aboriginal Health Council of South Australia Ltd. (AHCSA) Executive Officer – Aboriginal Health Research and Ethics Committee (AHREC)

From: Tina Brodie

Sent: Thursday, 10 September 2020 9:39 AM

To: Gokhan Ayturk

**Cc:** Natasha Howard ; Odette Pearson

Subject: RE: Modification Request for AHREC 04-18-791

Hi Gokhan,

Please find attached the clarifications as requested by the committee for out of session review.

Best wishes,

Tina Brodie BSW (Hons) GradCertCouns

PhD Candidate

Wardliparingga Aboriginal Health Equity

From: Gokhan Ayturk

Sent: Tuesday, 11 August 2020 11:17 AM

To: Tina Brodie

Subject: RE: Modification Request for AHREC 04-18-791

# APPENDIX 2.2: ADDRESSING THE SOCIAL DETERMINANTS OF INDIGENOUS HEALTH ADVISORY GROUP: TERMS OF REFERENCE



## Addressing the Social Determinants of Aboriginal Health – PhD Advisory Group Terms of Reference

#### 1. NAME

Addressing the Social Determinants of Aboriginal Health - PhD Advisory Group

#### 2. CONTEXT

Tina Brodie is a PhD Candidate enrolled at the University of South Australia and undertaking the project within the Wardliparingga Aboriginal Research Unit under the Principal Supervision of Prof Alex Brown and Co-Supervisors Dr Natasha Howard and Dr Odette Pearson. The PhD project is titled "Knowledge to Action: addressing the social determinants of Indigenous health to improve Aboriginal peoples' Social and Emotional Wellbeing."

The study aims to better understand: 1) the social and cultural status of Aboriginal people within the South Australian community context 2) service responses to addressing the social determinants of health and 3) evaluating the Cultural Pathways Program (a social determinants of health intervention) aimed at improving Aboriginal Social and Emotional Wellbeing.

#### 3. BACKGROUND

The disparities in health status for Aboriginal and Torres Strait Islander communities (hereafter respectfully referred to as Aboriginal) have been extensively documented. The effects of colonisation and the continuing social and political oppression and dispossession of Aboriginal communities has contributed to significant socio-economic and health status inequities.

The social conditions in which people live contribute to opportunities for healthy lives and include domains such as education, employment, income, housing, and transport. There is a pressing need to act on the social determinants of health which requires moving from knowledge of the importance of these determinants to purposefully addressing them. The PhD research addresses a significant knowledge gap on the social determinants of health for Aboriginal communities and provides the foundation to move from knowledge to action on the social determinants of health.

#### 4. AIM

The goal of the Advisory Group is to provide advice and guidance on how the project is implemented, findings are interpreted and recommendations for these findings to inform policy/systems/practice.

#### 5. OBJECTIVES

- 1. Provide advice on the implementation of the PhD project stages
- 2. Guide the interpretation of findings and results
- 3. Identify recommendations based on the information gathered
- 4. Inform the development of a plan on how to distribute the information (knowledge exchange)
- 5. Provide advice on the presentation of the information
- 6. Provide advice and advocacy to inform policy/systems/practice changes

#### 6. MEMBERSHIP

The Advisory Group will include Aboriginal knowledge and expertise and relevant industry expertise. To capture the large scope of knowledge required across multiple sectors as represented by the diverse social determinants of health a representative will be sought from the following groups:

- Aboriginal community members representative of community diversity (gender and age)
- Aboriginal Health Council of South Australia
- Council of Aboriginal Elders of South Australia
- SA Government Aboriginal Affairs (Aboriginal Affairs and Reconciliation Division)
- SA Health (Aboriginal Health Branch)
- Non-government social services (South Australian Council of Social Services)

#### Associate Membership

The Advisory Group may invite topic experts to join in addition to, or in place of, the existing membership for specific projects or activities. These would be agreed by the group. For example, representatives from broader social determinant domains would be invited to attend meetings as required.

#### Facilitation of Meetings

The Advisory Group will be facilitated by the PhD Candidate and membership and vacancies will be managed by the Candidate and supervisory team. We envisage that all members of the Advisory Group will experience an opportunity for two-way learning and capacity building.

#### 7. OPERATING PROCEDURES

#### a) Meetings

Meetings will be held *annually* at a boardroom in the South Australian Health and Medical Research Unit (SAHMRI), on North Terrace, Adelaide. The length of the meetings will be 2 hours or up to a half-day if necessary.

#### b) Flexible engagement

Additional meetings, one to one consultations and/or small focus groups will occur by negotiation with members depending on the stage of the project.

c) Project timeline and key engagement points (updated June 2020)



#### d) Agenda

- 1. Acknowledgement of Country
- 2. Apologies
- 3. Progress since last meeting (refer to action items also)
- 4. Items requiring discussion
- 5. Confirmation of action items to progress
- 6. Next meeting date

#### 8. EXPENSES TO ATTEND MEETINGS

Travel and where necessary accommodation expenses to attend meetings, will be paid for by Wardliparingga if an Advisory Group member is not supported to attend as part of their employment. Sitting fees for non-waged persons will be paid according to the Wardliparingga sitting fee policy.

#### 9. ADMINSTRATIVE SUPPORT

Wardliparingga will provide administrative support to the Advisory Group. The majority of work generated by the Advisory Group will be performed by the Wardliparingga Aboriginal Research Unit. An action-orientated list of work will be recorded and reported on at each meeting to assist with the progress and coordination of work. Where appropriate, business may be conducted via email and telecommunication (phone, teleconferencing and video links).

#### 10. CONFLICT OF INTEREST

Members of the reference group must declare to the Chair, any interest, potential conflict or apparent conflict of interest in matters that might be considered by the reference group.

#### 11. INTELLECTUAL PROPERTY

The Advisory Group will be acknowledged as contributors in the PhD thesis and any related publications.

# APPENDIX 3.1: MENTAL HEALTH AND SOCIAL DETERMINANTS OF HEALTH: ANALYSIS TABLES

Table 1: Mental Health Conditions Combined (F10-F19, F20-F29, F30-F39, F40-F48, F50-F59, F60-F69, F80-F89) by Public, Private, ED presentations (2011-2018 calendar year)

|                | Total<br>Population   |               |             |               |                |               |             |               |                |           |                      |               |                               |  |  |
|----------------|---|---------------|-------------|---------------|----------------|---------------|-------------|---------------|----------------|-----------|----------------------|---------------|-------------------------------|--|--|
| Landscape      | Aboriginal<br>and Torres<br>Strait<br>Islander<br>Persons 15+ | PU            | IBLIC HOSI  | PITALISATIC   | ONS            | PRI           | VATE HOS    | SPITALISAT    | TIONS          | EMI       | EMERGENCY DEPARTMENT |               |                               |  |  |
|                | Average<br>2011-2016  | All-<br>Cause | Total<br>MH | % total<br>mh | Av LoS<br>days | All-<br>Cause | Total<br>MH | % total<br>mh | Av LoS<br>days | All-Cause | Total MH             | % total<br>mh | Av.<br>Wait<br>time<br>(mins) |  |  |
| 1 Remote Far   |   |               |             |               |                |               |             |               |                |           |                      |               | ,                             |  |  |
| North          | 592   | 3,408         | 336         | 9.86%         | 4.82           | 17            | 1           | 5.88%         | 3.53           | 4,916     | 123                  | 2.50%         | 10.07                         |  |  |
| 2 Remote Far   |   |               |             |               |                |               |             |               |                |           |                      |               |                               |  |  |
| West           | 920   | 9,695         |             | 4.40%         | 2.23           | 21            | 0           |               |                |           |                      |               | 7.22                          |  |  |
| 3 Whyalla      | 681   | 12,029        | 424         | 3.52%         | 1.73           | 20            | 0           | 0.00%         | 3.15           | 5,425     | 355                  | 6.54%         | 13.70                         |  |  |
| 4 Port Augusta | 2116  | 41,370        | 1,334       | 3.22%         | 1.74           | 72            | 0           | 0.00%         | 1.89           | 23,169    | 1,147                | 4.95%         | 16.56                         |  |  |
| 5 South Eyre   |   |               |             |               |                |               |             |               |                |           |                      |               |                               |  |  |
| Peninsula      | 703   | 4,568         | 320         | 7.01%         | 2.55           | 39            | 0           | 0.00%         | 2.38           | 5,020     | 253                  | 5.04%         | 8.68                          |  |  |
| 6 North York   |   |               |             |               |                |               |             |               |                |           |                      |               |                               |  |  |
| Peninsula      | 1053  | 7,067         | 527         | 7.46%         | 2.73           | 121           | 1           |               |                |           | 384                  |               | <b>——</b>                     |  |  |
| 7 Riverland    | 685   | 4,431         | 471         | 10.63%        | 2.68           | 35            | 0           | 0.00%         | 1.74           | 4,389     | 573                  | 13.06%        | 5.54                          |  |  |

| 8 Murray Barker    |      |        |       |        |      |       |    |       |      |        |       |        |       |
|--------------------|------|--------|-------|--------|------|-------|----|-------|------|--------|-------|--------|-------|
| Fleurieu Coorong   | 1597 | 8,973  | 1,109 | 12.36% | 2.82 | 278   | 0  | 0.00% | 1.82 | 6,115  | 421   | 6.88%  | 13.14 |
|                    |      |        |       |        |      |       |    |       |      |        |       |        |       |
| 9 Rural South East | 724  | 2,254  | 283   | 12.56% | 3.69 | 82    | 0  | 0.00% | 1.72 | 2,962  | 180   | 6.08%  | 28.00 |
| 10 Outer North     |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 2227 | 12,866 | 834   | 6.48%  | 2.65 | 344   | 7  | 2.03% | 2.09 | 15,228 | 1,366 | 8.97%  | 55.92 |
| 11 Inner North     |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 1539 | 6,953  | 343   | 4.93%  | 2.68 | 413   | 9  | 2.18% | 2.29 | 7,290  | 710   | 9.74%  | 60.85 |
| 12 North East      |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 1815 | 11,504 | 1,223 | 10.63% | 4.33 | 660   | 3  | 0.45% | 1.75 | 10,788 | 1,325 | 12.28% | 51.12 |
| 13 City East       |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 798  | 4,389  | 751   | 17.11% | 8.60 | 1,046 | 5  | 0.48% | 2.03 | 5,385  | 982   | 18.24% | 50.78 |
| 14 Port North      |      |        |       |        |      |       |    |       |      |        |       |        |       |
| West Metro         | 1573 | 17,790 | 573   | 3.22%  | 2.54 | 416   | 3  | 0.72% | 1.59 | 9,640  | 925   | 9.60%  | 48.09 |
| 15 West Metro      | 1046 | 5,230  | 454   | 8.68%  | 3.93 | 528   | 0  | 0.00% | 1.85 | 5,767  | 749   | 12.99% | 48.59 |
| 16 Inner South     |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 1041 | 4,564  | 460   | 10.08% | 3.70 | 1,036 | 18 | 1.74% | 1.73 | 5,791  | 807   | 13.94% | 47.80 |
| 17 Outer South     |      |        |       |        |      |       |    |       |      |        |       |        |       |
| Metro              | 1395 | 5,993  | 465   | 7.76%  | 2.62 | 501   | 0  | 0.00% | 1.61 | 9,255  | 943   | 10.19% | 40.85 |

#### notes:

ED average waiting time based on available data: missing No.=85,123

)S based on all seperations

a All cause Total number of hospitalisations/OOS for all reasons

b Total MH Total Mental Health Hospitalisations/OOS

c n number of hosptalisations/OSS for the specific mental health condition (e.g. ICD F10-F19)

d % all cause  $\,$  c divided by a multiple 100

e % total MH c divided by b multiple 100

Table 2: Mental Health Conditions Combined (F10-F19, F20-F29, F30-F39, F40-F48, F50-F59, F60-F69, F80-F89) by Public, Private, ED presentations and hospitalistaions (2011-2018) calendar year) and Social Determinant of Health: Education Attainment

|                                     | Total Population  |                            |                     |                    |       |        |       | EDUC    | ATION |     |                 |     |        |
|-------------------------------------|---|----------------------------|---------------------|--------------------|-------|--------|-------|---------|-------|-----|-----------------|-----|--------|
| Landscape                           | Aboriginal and Torres<br>Strait Islander Persons<br>15+ | Public<br>Hospitalisations | ED<br>Presentations | Year 9 or<br>below |       | Voor 1 |       | Year 12 |       |     | not go<br>chool | Not | Stated |
|                                     | Average 2011-2016                                       | Rate per 1,000             | Rate per 1,000      | n                  | n %   |        | %     | n       | %     | n   | %               | n   | %      |
| 1 Remote Far North                  | 592   | 567                        | 208                 | 112                | 23.63 | 195    | 41.14 | 112     | 23.63 | 25  | 5.27            | 54  | 11.39  |
| 2 Remote Far West                   | 920   | 464                        | 663                 | 145                | 20.45 | 244    | 34.41 | 114     | 16.08 | 0   | 0               | 206 | 29.06  |
| 3 Whyalla                           | 681   | 623                        | 521                 | 98                 | 16.81 | 289    | 49.57 | 142     | 24.36 |     | 0               | 54  | 9.26   |
| 4 Port Augusta                      | 2116  | 630                        | 542                 | 327                | 17.58 | 807    | 43.39 | 320     | 17.2  | 20  | 1.08            | 386 | 20.75  |
| 5 South Eyre Peninsula              | 703   | 455                        | 360                 | 96                 | 16.99 | 225    | 39.82 | 120     | 21.24 | <10 | 0               | 124 | 21.95  |
| 6 North York Peninsula              | 1053  | 500                        | 364                 | 184                | 20.18 | 446    | 48.9  | 199     | 21.82 | <10 | 0               | 83  | 9.1    |
| 7 Riverland                         | 685   | 687                        | 836                 | 144                | 23.57 | 275    | 45.01 | 126     | 20.06 | <10 | 0               | 66  | 10.8   |
| 8 Murray Barker Fleurieu<br>Coorong | 1597  | 694                        | 264                 | 225                | 18.63 | 607    | 50.25 | 376     | 31.13 | <10 | 0               | 0   | 0      |
| 9 Rural South East                  | 724   | 391                        | 248                 | 98                 | 15.86 | 298    | 48.22 | 159     | 25.73 | 0   | 0               | 63  | 10.19  |
| 10 Outer North Metro                | 2227  | 374                        | 613                 | 319                | 15.6  | 973    | 47.58 | 618     | 30.22 | 18  | 0.88            | 117 | 5.72   |
| 11 Inner North Metro                | 1539  | 223                        | 461                 | 210                | 16.56 | 626    | 49.37 | 432     | 34.07 | 0   | 0               | 0   | 0      |
| 12 North East Metro                 | 1815  | 674                        | 730                 | 187                | 12.11 | 619    | 40.09 | 478     | 30.96 | 15  | 0.97            | 245 | 15.87  |
| 13 City East Metro                  | 798   | 941                        | 1231                | 73                 | 10.35 | 227    | 32.2  | 331     | 46.95 | 0   | 0               | 74  | 10.5   |
| 14 Port North West Metro            | 1573  | 364                        | 588                 | 198                | 15.4  | 610    | 47.43 | 412     | 32.04 | <10 | 0               | 66  | 5.13   |
| 15 West Metro                       | 1046  | 434                        | 716                 | 71                 | 15.37 | 176    | 38.1  | 198     | 42.86 | <10 | 0               | 17  | 3.68   |
| 16 Inner South Metro                | 1041  | 442                        | 775                 | 119                | 12.16 | 404    | 41.27 | 421     | 43    | <10 | 0               | 35  | 3.58   |
| 17 Outer South Metro                | 1395  | 333                        | 676                 | 150                | 12.57 | 552    | 46.27 | 437     | 36.4  | <10 | 0               | 54  | 4      |

Table 3: Mental Health Conditions Combined (F10-F19, F20-F29, F30-F39, F40-F48, F50-F59, F60-F69, F80-F89) by Public, Private, ED presentations and hospitalistaions (2011-2018) calendar year) and Social Determinant of Health: Employment Status

|                                     | Total Population   |                            |                  | EMPLOYMENT |       |      |         |                 |                                |      |        |  |  |  |
|-------------------------------------|--|----------------------------|------------------|------------|-------|------|---------|-----------------|--------------------------------|------|--------|--|--|--|
| Landscape                           | Aboriginal and<br>Torres Strait<br>Islander Persons<br>15+ | Public<br>Hospitalisations | ED Presentations | Emplo      | oyed  | Unem | nployed | partic<br>in la | lot<br>ipating<br>ibour<br>rce | Not: | Stated |  |  |  |
|                                     | Average 2011-2016  | Rate per 1,000             | Rate per 1,000   | n          | %     | n    | %       | n               | %                              | n    | %      |  |  |  |
| 1 Remote Far North                  | 592  | 567                        | 208              | 198        | 38.67 | 30   | 5.86    | 236             | 46.09                          | 48   | 9.38   |  |  |  |
| 2 Remote Far West                   | 920  | 464                        | 663              | 212        | 28.96 | 30   | 4.1     | 292             | 39.89                          | 198  | 27.05  |  |  |  |
| 3 Whyalla                           | 681  | 623                        | 521              | 203        | 31.52 | 83   | 12.89   | 330             | 51.24                          | 28   | 4.35   |  |  |  |
| 4 Port Augusta                      | 2116   | 630                        | 542              | 639        | 32.21 | 217  | 10.94   | 1012            | 51.01                          | 116  | 5.85   |  |  |  |
| 5 South Eyre Peninsula              | 703  | 455                        | 360              | 201        | 32.9  | 59   | 9.66    | 306             | 50.08                          | 45   | 7.36   |  |  |  |
| 6 North York Peninsula              | 1053   | 500                        | 364              | 326        | 31.47 | 122  | 11.78   | 553             | 53.8                           | 35   | 3.38   |  |  |  |
| 7 Riverland                         | 685  | 687                        | 836              | 232        | 34.68 | 55   | 8.22    | 355             | 53.06                          | 27   | 4.04   |  |  |  |
| 8 Murray Barker Fleurieu<br>Coorong | 1597   | 694                        | 264              | 591        | 38.91 | 126  | 8.29    | 784             | 51.61                          | 18   | 1.18   |  |  |  |
| 9 Rural South East                  | 724  | 391                        | 248              | 348        | 50.66 | 48   | 6.99    | 291             | 42.36                          | 0    | 0      |  |  |  |
| 10 Outer North Metro                | 2227   | 374                        | 613              | 875        | 38.8  | 241  | 10.69   | 1093            | 48.47                          | 46   | 2.04   |  |  |  |
| 11 Inner North Metro                | 1539   | 223                        | 461              | 660        | 43.36 | 165  | 10.84   | 669             | 43.96                          | 28   | 1.84   |  |  |  |
| 12 North East Metro                 | 1815   | 674                        | 730              | 637        | 36.74 | 156  | 9       | 907             | 52.31                          | 34   | 1.96   |  |  |  |
| 13 City East Metro                  | 798  | 941                        | 1231             | 382        | 47.39 | 68   | 8.44    | 345             | 42.8                           | 11   | 1.36   |  |  |  |
| 14 Port North West Metro            | 1573   | 364                        | 588              | 624        | 41.08 | 149  | 9.81    | 711             | 46.81                          | 35   | 2.3    |  |  |  |
| 15 West Metro                       | 1046   | 434                        | 716              | 462        | 43.38 | 104  | 9.77    | 481             | 45.16                          | 18   | 1.69   |  |  |  |
| 16 Inner South Metro                | 1041   | 442                        | 775              | 527        | 48.8  | 79   | 7.31    | 474             | 43.89                          | 0    | 0      |  |  |  |
| 17 Outer South Metro                | 1395   | 333                        | 676              | 606        | 44    | 131  | 9       | 604             | 44                             | 37   | 3      |  |  |  |

Table 4: Mental Health Conditions Combined (F10-F19, F20-F29, F30-F39, F40-F48, F50-F59, F60-F69, F80-F89) by Public, Private, ED presentations and hospitalistaions (2011-2018) calendar year) and Social Determinant of Health: Housing

|                | Total<br>Population  |                            |                  | HOUSING |               |     |               |     |               |             |              |     |               |     |        |  |  |
|----------------|--|----------------------------|------------------|---------|---------------|-----|---------------|-----|---------------|-------------|--------------|-----|---------------|-----|--------|--|--|
| Landscape      | Aboriginal and<br>Torres Strait<br>Islander<br>Persons 15+ | Public<br>Hospitalisations | ED Presentations |         | ed or<br>/ing |     | nted<br>ately |     | blic<br>ısing | "Sec<br>Hou | ure"<br>sing |     | her<br>Illing | Not | Stated |  |  |
|                | Average 2011-<br>2016                                      | Rate per 1,000             | Rate per 1,000   | n       | %             | n   | %             | n   | %             | n           | %            | n   | %             | n   | %      |  |  |
| 1 Remote Far   |  |                            |                  |         |               |     |               |     |               |             |              |     |               |     |        |  |  |
| North          | 592  | 567                        | 208              | 41      | 19.7          | 56  | 26.9          | 111 | 53.4          | 208         | 100          | 0   | 0             | 0   | 0      |  |  |
| 2 Remote Far   |  |                            |                  |         |               |     |               |     |               |             |              |     |               |     |        |  |  |
| West           | 920  | 464                        | 663              | 66      | 19.1          | 76  | 22            | 169 | 48.8          | 311         | 89.9         | 0   | 0             | 35  | 10.01  |  |  |
| 3 Whyalla      | 681  | 623                        | 521              | 79      | 17.9          | 70  | 15.8          | 22  | 5             | 171         | 38.7         | 244 | 55.2          | 27  | 6.1    |  |  |
| 4 Port Augusta | 2116   | 630                        | 542              | 294     | 28.5          | 212 | 20.6          | 199 | 19.3          | 705         | 68.4         | 278 | 27            | 47  | 4.6    |  |  |
| 5 South Eyre   |  |                            |                  |         |               |     |               |     |               |             |              |     |               |     |        |  |  |
| Peninsula      | 703  | 455                        | 360              | 92      | 24.8          | 93  | 25.1          | 101 | 27.2          | 286         | 77.1         | 71  | 19            | 14  | 3.8    |  |  |
| 6 North York   |  |                            |                  |         |               |     |               |     |               |             |              |     |               |     |        |  |  |
| Peninsula      | 1053   | 500                        | 364              | 316     | 44            | 215 | 29.9          | 74  | 10.3          | 605         | 84.3         | 87  | 12.1          | 26  | 3.6    |  |  |
| 7 Riverland    | 685  | 687                        | 836              | 165     | 37.1          | 121 | 27.2          | 89  | 20            | 375         | 84.3         | 55  | 12.4          | 15  | 3.4    |  |  |

|                  |      |     |      |     |      |     |      |     |      |      |      |     | 1    |    |     |
|------------------|------|-----|------|-----|------|-----|------|-----|------|------|------|-----|------|----|-----|
|                  |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| 8 Murray Barker  |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Fleurieu Coorong | 1597 | 694 | 264  | 382 | 38.1 | 322 | 32.1 | 175 | 17.4 | 879  | 87.6 | 85  | 8.5  | 39 | 3.9 |
| 9 Rural South    |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| East             | 724  | 391 | 248  | 257 | 48.1 | 134 | 25.1 | 37  | 6.9  | 428  | 80.1 | 94  | 17.6 | 12 | 2.2 |
| 10 Outer North   |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 2227 | 374 | 613  | 546 | 32.6 | 538 | 32.1 | 126 | 7.5  | 1210 | 72.2 | 407 | 24.3 | 60 | 3.6 |
| 11 Inner North   |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 1539 | 223 | 461  | 402 | 39.1 | 274 | 26.7 | 192 | 18.7 | 868  | 84.4 | 160 | 15.6 | 0  | 0   |
| 12 North East    |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 1815 | 674 | 730  | 299 | 27.7 | 244 | 22.6 | 265 | 24.5 | 808  | 74.7 | 235 | 21.7 | 38 | 3.5 |
| 13 City East     |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 798  | 941 | 1231 | 118 | 22.6 | 101 | 19.4 | 20  | 3.8  | 239  | 45.9 | 271 | 52   | 11 | 2.1 |
| 14 Port North    |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| West Metro       | 1573 | 364 | 588  | 248 | 24.3 | 171 | 16.8 | 203 | 19.9 | 622  | 61   | 372 | 36.5 | 25 | 2.5 |
| 15 West Metro    | 1046 | 434 | 716  | 181 | 24.4 | 158 | 21.3 | 91  | 12.3 | 430  | 58   | 278 | 37.5 | 34 | 4.6 |
| 16 Inner South   |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 1041 | 442 | 775  | 283 | 34.9 | 162 | 20   | 90  | 11.1 | 535  | 65.9 | 246 | 30.3 | 31 | 3.8 |
| 17 Outer South   |      |     |      |     |      |     |      |     |      |      |      |     |      |    |     |
| Metro            | 1395 | 333 | 676  | 425 | 38.8 | 364 | 33.2 | 138 | 12.6 | 927  | 84.6 | 138 | 12.6 | 31 | 2.8 |

Table 5: Mental Health Conditions Combined (F10-F19, F20-F29, F30-F39, F40-F48, F50-F59, F60-F69, F80-F89) by Public, Private, ED presentations and hospitalistaions (2011-2018) calendar year) and Social Determinant of Health: Income

|                          | Total Population   |                            |                  | INCOME  |       |  |       |       |       |  |  |
|--------------------------|--|----------------------------|------------------|---|-------|--|-------|-------|-------|--|--|
| Landscape                | Aboriginal and<br>Torres Strait<br>Islander Persons<br>15+ | Public<br>Hospitalisations | ED Presentations | Households with<br>Equivalised weekly<br>income below \$999 |       | Households with<br>Equivalised weekly<br>income above \$1000 |       | Other |       |  |  |
|                          | Average 2011-<br>2016                                      | Rate per 1,000             | Rate per 1,000   | n   | %     | n  | %     | n     | %     |  |  |
| 1 Remote Far North       | 592  | 567                        | 208              | 83  | 42.56 | 57   | 29.23 | 55    | 28.21 |  |  |
| 2 Remote Far West        | 920  | 464                        | 663              | 108   | 30.68 | 111  | 31.53 | 133   | 37.78 |  |  |
| 3 Whyalla                | 681  | 623                        | 521              | 233   | 54.06 | 147  | 34.11 | 51    | 11.83 |  |  |
| 4 Port Augusta           | 2116   | 630                        | 542              | 442   | 43.76 | 381  | 37.72 | 187   | 18.51 |  |  |
| 5 South Eyre Peninsula   | 703  | 455                        | 360              | 156   | 43.33 | 147  | 40.83 | 57    | 15.83 |  |  |
| 6 North York Peninsula   | 1053   | 500                        | 364              | 402   | 52.89 | 268  | 35.26 | 90    | 11.84 |  |  |
| 7 Riverland              | 685  | 687                        | 836              | 208   | 49.64 | 162  | 38.66 | 49    | 11.69 |  |  |
| 8 Murray Barker Fleurieu |  |                            |                  |   |       |  |       |       |       |  |  |
| Coorong                  | 1597   | 694                        | 264              | 457   | 44.94 | 436  | 42.87 | 124   | 12.19 |  |  |
| 9 Rural South East       | 724  | 391                        | 248              | 232   | 42.73 | 238  | 43.83 | 73    | 13.44 |  |  |
| 10 Outer North Metro     | 2227   | 374                        | 613              | 749   | 45.39 | 732  | 44.36 | 169   | 10.24 |  |  |
| 11 Inner North Metro     | 1539   | 223                        | 461              | 427   | 39.57 | 532  | 49.3  | 120   | 11.12 |  |  |
| 12 North East Metro      | 1815   | 674                        | 730              | 443   | 40.72 | 520  | 47.79 | 125   | 11.49 |  |  |
| 13 City East Metro       | 798  | 941                        | 1231             | 196   | 39.76 | 260  | 52.74 | 37    | 7.51  |  |  |
| 14 Port North West Metro | 1573   | 364                        | 588              | 461   | 44.76 | 445  | 43.2  | 124   | 12.02 |  |  |
| 15 West Metro            | 1046   | 434                        | 716              | 297   | 38.22 | 393  | 50.58 | 87    | 11.2  |  |  |
| 16 Inner South Metro     | 1041   | 442                        | 775              | 262   | 33.55 | 445  | 56.98 | 74    | 9.48  |  |  |
| 17 Outer South Metro     | 1395   | 333                        | 676              | 462   | 43    | 457  | 42.4  | 157   | 14.5  |  |  |

#### notes:

**Total Population:** Sourced from Landscape Report Chapter 2: Population Context, Table 2.5.1. to calculate the average population 2011-2016 **Puplic Hospitalisations:** Rate of Public Hospitalisations for mental and behavioural disorders (ICD\_10\_AM Chapter V) per 1,000 for or the place of residence (Landscape) at hospitalisation. Data Source: ISAAC, SA Department of Health and Ageing

Emergency Department Presentation: Rate of Emergency Department Presentations for mental and behavioural disorders (ICD\_10\_AM Chapter V) per

**Education:** Proportion of Aboriginal and Torres Strait Islander People >15yrs by highest year of school completed: Year 9 or below; Year 10-11 and Year 12 or equivalent.

**Employment:** Proportion of Aboriginal and Torres Strait Islander People who are employed, unemployed or not participating in the labour force. **Housing:** Aboriginal and Torres Strait Islander Households with Secure Housing (buying, rented or public housing) and Other Dwellings (caravans, tents or improvised homes)

Income: Aboriginal and Torres Strait Islander Households Weekly equivalised household income above \$1,000 or below \$999

# APPENDIX 4.1: SUBMITTED MANUSCRIPT ENHANCEMENT OF SCOPING REVIEW METHODOLOGY TO REFLECT ABORIGINAL AND TORRES STRAIT ISLANDER WAYS OF KNOWING, BEING AND DOING

- 1 Enhancement of scoping review methodology to reflect Aboriginal and Torres Strait
- 2 Islander ways of knowing, being and doing

- 4 Abstract
- 5 *Objective*: This paper argues for the enhancement of the scoping review method to
- 6 incorporate Indigenous ways of knowing, being and doing for more effective understandings
- 7 of evidence of importance to Indigenous populations.
- 8 *Methods*: Scoping review methodology typically aims to understand existing evidence and
- 9 support translation of evidence into practice. Levac and colleagues (2010) scoping review
- methodology six stages 1) Identify the research question; 2) Identify relevant studies; 3)
- 11 Study selection; 4) Charting the data; 5) Collating, summarizing and reporting results; and 6)
- 12 Consultation were considered from the perspective of Indigenous knowledges and adapted
- 13 accordingly.
- 14 *Results:* The scoping review method can be enhanced to better align with Indigenous
- methodologies which are based on relationality, collaboration, partnership, reciprocity, and
- benefit. Consultationwas redefined in this enhancement as *partnership* and integrated
- throughout the scoping review stages, which are underpinned by key methodological
- 18 principles.
- 19 *Conclusions:* An enhancement of the scoping review stages with Indigenous ways of
- 20 knowing, being and doing has the potential to strengthen the utility of the scoping review
- 21 method to better meet the needs of and ensure relevance for Indigenous populations.
- 22 Implications for public health: These enhancements can increase the potential for
- 23 knowledge translation and implementation of culturally relevant evidence-based approaches

into practice for Indigenous populations and for other populations who experience healthinequities.

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# **Keywords**

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- 29 Indigenous Knowledge; Aboriginal and Torres Strait Islander Knowledge; Methodological
- 30 Framework; Scoping review; Knowledge Translation; Culturally Responsive; Indigenous
- 31 Engagement; Participatory.

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# **Objective**

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Research with Indigenous\* communities and by Indigenous researchers has continued to 35 evolve over time. The majority of research with Indigenous populations, prior to the 1990s, 36 37 had been characterised by dominant discourses and legacies of ethno-centrism which 38 problematised communities and positioned Western science as having the only solutions to "Indigenous problems". These discourses have failed to recognise the contextual influences 39 of racism, discrimination, dispossession and oppression in the creation of these 'problems' 2-6. 40 41 The emergence of Indigenous and decolonising methodologies by Indigenous academics throughout the 1990's, which prioritised Indigenous wisdom and knowledges, coincided with 42 a shift towards the implementation of ethical research frameworks<sup>1,6,7</sup>. Additionally, the 43 emergence of social sciences, feminism and participatory approaches offered alternative 44

points of view and challenged prevailing and dominant discourses of non-Indigenous

<sup>\*</sup>The term Indigenous is used to refer globally to Indigenous or First Nations populations including Aboriginal and Torres Strait Islander populations. Aboriginal and Torres Strait Islander is used when referring specifically to this context and population.

research<sup>1,6,8</sup>. In an Australian context, the emergence of accountability and ethical structures have been embedded in health research to ensure quality and safety of research with Indigenous communities. These structures contribute to research projects which are relevant, effective and respectful<sup>9-13</sup>.

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The emergence of Indigenous methodologies was an active reclamation of space, of colonial resistance and self-determination.<sup>7</sup> Indigenous scholars in Australia and New Zealand created opportunities for the prioritisation of Indigenous methodologies and methods that are both culturally relevant and responsive to the needs of Indigenous communities<sup>7,14,15</sup>. An Indigenous methodology is underpinned by ontology (ways of being / how we perceive our reality), epistemology (ways of knowing / how we think about it), and axiology (ways of doing / values and beliefs). An Indigenous methodology from an Aboriginal and Torres Strait Islander perspective requires that research responds to community driven priorities, is of benefit to the community and is grounded in relationality, partnerships, and reciprocity<sup>1,5,7,14,15</sup>. An Indigenous methodology can include both Indigenous and non-Indigenous methods, however, it is always consistent with Indigenous ways of knowing, being and doing. Indigenous methodologies centre Indigenous knowledge and understanding and then identify the most appropriate method to meet that need<sup>1</sup>. Those methods are then adapted as necessary through the process of decolonising. Decolonising is an approach which involves unravelling and challenging dominant or Eurocentric discourses across systems and structures<sup>7</sup>. An example in a research context of decolonising methods is to challenge dominant methods which can contribute to or perpetuate oppression and disempower communities<sup>7</sup>. Decolonising methods on their own are applied within predominantly Western frameworks to adapt methodologies and methods to incorporate or better suit Indigenous ways of knowing, being and doing<sup>7</sup>.

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Reviewing literature and evidence can be a culturally relevant way to communicate with "dominant system academia". The process of reviewing evidence acknowledges and builds upon cultural knowledge and stories by sharing what is already known from an evidencebased perspective. For Indigenous contexts and populations, culturally relevant understandings can enhance implementation and uptake of research and more effectively translate into improved health and wellbeing outcomes<sup>7,16,17</sup>. The process of integrating cultural ways of knowing, being and doing, particularly story-telling and sharing, with processes for systematically reviewing evidence is not common in health research. From an Indigenous knowledge perspective, the process of sharing or storytelling is consistent with cultural practices. Within non-Indigenous research, reviews of evidence are conducted across diverse contexts for different reasons, questions of interest and evidence types. The two most common review types include systematic reviews, which emerged in the 1980s and more recently scoping reviews, both have increased in use throughout the 2000's as part of a growing emphasis on evidence-based health care 18,35. The process of systematically reviewing primary research enables the documentation of understandings of what has been tried, effectiveness, gaps in evidence, and informs evidence-based practice in health services and systems<sup>18</sup>. A scoping review method<sup>19</sup> is well suited for topics which require access to a breadth of peer reviewed and grey literature and therefore is particularly useful for understandings and research questions of importance to Aboriginal and Torres Strait Islander populations<sup>20</sup>. The scoping review method outlined in published review guidelines outlines six stages: 1) Identify the research question; 2) Identify relevant studies; 3) Study selection; 4) Charting Data; 5) Collating, reporting and summarising the results; and 6) Consultation<sup>21</sup>. Scoping review methods have continued to be enhanced to enable consistent and standardised approaches, although, there are still inconsistencies in applying

these guidelines<sup>18,21-23</sup>. For example, an evaluation of the methodology in 2014 highlighted the need for clarity for inclusion criteria and presentation of results<sup>44</sup>. Further, inconsistency in the conduct of reviews resulted in clearer guidance developed by JBI (Joanna Briggs Institute) with an aim to improve the utility of the method<sup>18</sup>. Participatory, collaborative and consumer driven research continues to gain momentum internationally with health services increasingly implementing consumer engagement strategies and researchers considering how they can involve consumers and stakeholders in the research process<sup>8,24</sup>. Despite this focus, published scoping reviews rarely describe the processes undertaken within the consultation stage, or undertake this stage at all<sup>23,41</sup>. This paper argues that through prioritising Indigenous ways of knowing, being and doing this process can not only contribute to, but enhance, scoping review methods.

# Methods

The described methodological enhancement (Table 1) was developed and implemented by [name and location removed]. Consistent with an Indigenous methodology, the authors are part of and work with Indigenous communities<sup>25</sup> and adhere to the ways of working defined by the [location removed] Aboriginal and Torres Strait Islander community. The [blinded

reference]<sup>9</sup> requires that research is informed by community priorities, designed in partnership and benefits Aboriginal and Torres Strait Islander peoples and communities. Indigenous methodology principles of reciprocity, partnership, co-design and collaboration can be embedded into existing scoping review methods which currently include consultation and engagement<sup>1,3</sup>. The expanded method detailed in this manuscript allows for a collaborative approach that prioritises Indigenous knowledge, expertise and engagement. The first enhancement of the scoping review methodology was to reconceptualise the stage of consultation to partnership which is grounded in relationality and integrated throughout the review stages. For the method described in this paper, the inclusion of Indigenous knowledges and expertise was embedded through an Advisory Group. The group was established with membership specifically selected for the research question. Membership includes both Indigenous community and relevant industry stakeholder knowledge and expertise. The Advisory Group is governed by Terms of Reference and the goal of the group is to provide advice and guidance on implementation, interpretation of findings and to inform recommendations which influence health systems, policy and practice. This manuscript outlines the process, benefits, challenges, and opportunities for expanding the scoping review method to integrate Indigenous knowledges. The following sections detail the Indigenous informed methodological enhancements for a partnership approach to the scoping review stages.

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# Table 1: Scoping Review Methodology – Integrating Indigenous Knowledge

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## Results and Discussion: The enhancements

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# 1. Partnership

Participatory approaches are increasingly used in Indigenous research because of their ability to recognise that people are influenced by the contexts in which they live<sup>8,26,27</sup>. Participatory research is underpinned by partnership approaches which involve researchers and stakeholders collaboratively working together in the implementation and translation of research<sup>8,44</sup>. Partnership approaches to research with Aboriginal and Torres Strait communities should be grounded in the establishment of mutual trust that enables Aboriginal and Torres Strait Islander people to have an integral role in research which effects their lives and communities<sup>9</sup>. Partnership approaches described in this enhancement are based on relationships and collaborative processes which move beyond consultation. Approaches which keep the end-user in mind when planning and implementing research, require that research priorities and questions align with community needs<sup>24</sup>. Priorities for research should arise from and have the endorsement of the community <sup>9,10,13</sup>. The involvement of community and key stakeholders in developing research proposals and plans enhances acceptability, relevance and accountability<sup>24</sup>. Governance structures such as Reference Groups or Advisory Groups are often established to ensure that research addresses community priorities and enables the community to inform the methods and provide guidance throughout the research process<sup>9,10,13,28,29</sup>. Approaches to governance, including membership, meetings and frequency can be flexible depending on the research project and question. Partnership approaches should be genuinely considered and integrated throughout the research process<sup>9,30</sup>. Such approaches enable the integration of knowledges for enhanced meaning, understanding and interpretation of research findings strengthening their relevance and ability to meet community identified priorities.

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### 2. Identify the Scoping Review research question

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The starting point for a scoping review requires careful consideration to identify the question which will subsequently shape a clear purpose or aim, the search strategy and inclusion criteria<sup>19,21</sup>. Detailed processes to identify the review question will allow for parameters and implications of specifying particular population groups, interventions or outcomes to be fully considered<sup>19</sup>. For a scoping review it is recommended that review questions are broad with a clearly articulated scope of inquiry<sup>19,21</sup>. The recommended approach for scoping reviews includes defining the population, concept and context. A partnership approach can be achieved from the inception of the review by being guided by ethical research and accountability processes defined by Indigenous peoples<sup>9-12</sup>. A collaborative process can ensure that the review question and criteria are consistent with community identified needs and informed by the lived experience of Aboriginal and Torres Strait Islander communities. Through collaboration, consideration can be given to potential challenges that may be encountered in accessing information and support the early identification of strategies that could be implemented in the method. For the enhanced method the authors co-produced the research questions with the Advisory Group, presenting a draft question and review protocol for discussion to clarify, enhance and deepen the relevance of the question. A workshop discussion defined the aim and objectives of the review and refinements were made as needed based on feedback and discussions with the Advisory Group. For example, to enhance the review question, the Advisory Group suggested that the question could be made more explicit and identified the need for a clear definition of a health care program as well as suggesting a depiction of the type of programs that definition would include.

# 3. Identify relevant studies

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The process of identifying relevant studies or searching requires a comprehensive strategy to achieve breadth and depth in the identification of primary studies, published and unpublished, suitable for answering the review question 19,21,22. Practical decisions are made about the scope of the review, decisions justified, and limitations considered<sup>21,22</sup>. A team should be assembled at this stage with appropriate methodological and context expertise<sup>21</sup>. Consistent with Indigenous methodologies, ways of knowing, being and doing must be embedded in all matters and contexts which concern Indigenous communities, from research to policy making and practice<sup>12</sup>. Searching can include electronic databases, reference lists, hand-searching of key journals and exploration of existing networks<sup>19</sup>. The search itself can be consistent with the guidelines, with a search strategy implemented to identify peer-reviewed publications and grey literature. In developing the search strategy, the expertise of the research team and the Advisory Group should be utilised to access key grey literature search engines (e.g. Australian Indigenous HealthInfoNet and The Lowitja Institute) relevant to Aboriginal and Torres Strait Islander health publishing<sup>31,32</sup>. To integrate a partnership approach as part of the enhanced method, the Advisory Group informed the search strategy and supported identification of additional sources and key authors. This strategy enabled the identification of sources containing important data from a cultural and/or social perspective which would otherwise be left behind or excluded by relying solely on peer review and grey literature database searching or due to stringent criteria. In recognition of the many demands often placed upon community members and

leaders this approach was highly flexible and consultations included email and face to face conversations to identify additional programs.

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# 4. Study selection

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The scoping review method recommends the development of inclusion and exclusion criteria which are based on the review question<sup>18</sup>. Study selection is an iterative process which involves searching the literature, refining the search strategy and reviewing articles for inclusion<sup>21</sup>. Levac et al<sup>21</sup> recommend that the criteria are reviewed and discussed by the team for consistency and that reviewers assess abstracts independently, with a process in place for a third reviewer to resolve any disagreement. As part of the iterative process, reviewer meetings can be held at the beginning, middle and end for clarifications, to discuss challenges or to refine search strategy or criteria if needed<sup>22</sup>. When considering complex research questions or concepts for Indigenous research, Indigenous researchers with cultural knowledge and lived experiences are best placed to consider the nuances, complexities, histories and cultural understandings of phenomena that may not otherwise be understood<sup>1,3,7,14,15</sup>. For Indigenous populations or other population groups marginalised or harmed by previous research practices, the comprehensive cultural knowledge and understanding of the researcher not only contributes to quality, but also to safety for the population of interest<sup>33,34</sup>. A scoping review aims to provide a broad overview or assist in mapping evidence and is not usually intended to produce a critically appraised and synthesised result or answer to a question<sup>35</sup>. Therefore, critical appraisal is not required as part of the scoping review method but can be undertaken if it aligns with the scoping review aim<sup>35</sup>. To ensure culturally relevant understandings specifically for Aboriginal and Torres

Strait Islander populations an appraisal from a cultural perspective can be undertaken using The Aboriginal and Torres Strait Islander Quality Appraisal Tool: appraising research quality from an Aboriginal and Torres Strait Islander perspective (APPENDIX 1)<sup>17,36</sup>. For the enhanced method the study selection criteria were developed in collaboration with the Advisory Group and implemented to assess programs for eligibility. Reviewers included Indigenous researchers e.g. both Aboriginal and Torres Strait Islander researchers with cultural and contextual knowledge. This supported an objective process which was culturally grounded. Consistent with the method, the two reviewers met beforehand to discuss context and mutual understandings of the topic and/or question of interest and then were guided by the criteria to independently assess the studies for inclusion. The utilisation of the quality appraisal tool as part of this described enhanced method was not specifically for study inclusion and as such is described in the charting the data stage below. The Advisory Group remained informed of potential refinements with advice sought for critical changes. The PRISMA diagram was presented to provide an opportunity for the review to be guided by their cultural knowledge and lived experience. These approaches honour in practice that Indigenous people are the experts about their own lives and empowering for all involved 1,7,17,33

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# 5. Charting Data

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For included studies, data are charted according to elements such as the study population, type of intervention, outcome or measures<sup>19</sup>. It is recommended that a data charting form, which will determine the variables to extract, should be developed collectively with the research team.. This is an iterative process which allows for continually updating the form to

include data if required<sup>21</sup>. Scoping Review approaches which are seeking breadth can allow data of cultural and contextual relevance to be collected and included in a systematic way<sup>21</sup>. The Aboriginal and Torres Strait Islander Quality Appraisal Tool introduced above in the study selection stage, can ensure charting of data which is relevant for Aboriginal and Torres Strait Islander questions of interest<sup>17,36</sup>. The tool has utility not only for inclusion/exclusion purposes but to enhance cultural meaning and understandings relevant to the population of interest. The tool was developed specifically for the appraisal of literature reviewed for Aboriginal and Torres Strait Islander questions of interest. The questions in the tool are consistent with Aboriginal and Torres Strait Islander ways of knowing, being and doing and principles of Indigenous methodologies. The questions cover whether the research was a need or priority determined by the community, consultation and engagement, leadership and governance, community and cultural protocols. Questions also include intellectual and cultural property rights, benefits, translation and whether the research was strengths based and informed by an Indigenous research paradigm. Evidence indicates that research which is reflective of community values, priorities and perspectives can contribute to more relevant and meaningful outputs for Aboriginal and Torres Strait Islander people with a greater potential for knowledge translation<sup>36</sup>.

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The enhanced partnership approach was implemented with Advisory Group input into the extraction tool to ensure that information collected was relevant. A draft extraction tool was developed and included refinements based on feedback from the Advisory Group and throughout the process of data extraction. In charting the data, *The Aboriginal and Torres*Strait Islander Quality Appraisal Tool<sup>36</sup> was utilised for the purpose of systematically assessing/reviewing and charting types of studies and features from a cultural perspective and this information was included as results.

# 6. Collating, reporting and summarising the results

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The analysis in scoping reviews, also described as collating or summarising results, often includes descriptive numerical summaries to describe the overall number of included studies and their characteristics<sup>21</sup>. Reporting the results requires consideration of the intended outcome and then presenting findings in a way that is best able to do that. To enhance the process, it is recommended that the implications are considered within a broader context including for research, policy and practice <sup>43</sup>. Through the purposeful consideration of analyses there is a greater ability to have translation of results that inform further research, policy and practice<sup>21</sup>. It is imperative that Indigenous communities have ownership and control over Indigenous knowledge and that communities are actively involved in giving meaning to data about them and planning for its use<sup>9,10,13</sup>. Using preliminary findings to consult with stakeholders can build on the evidence and offer a higher level of meaning, content expertise and perspectives<sup>21</sup>. Aboriginal and Torres Strait Islander communication styles, such as thoughtful, deep listening, thinking, reflecting and considering, are processes which may take time<sup>42</sup>. Further, consideration should be given to the cultural responsibilities and community priorities of Advisory Group members, these factors can inform the approach for engagement and capacity of Advisory Group members to engage with the research project at any time<sup>9,10,13</sup>. Flexible approaches are required by the researcher to develop and maintain relationships with the community and key decision makers and leaders throughout the entire research cycle<sup>9,10,13</sup>. This enables an integrated and embedded approach to knowledge translation and the ability for research findings to influence policy and practice<sup>9,10,13,37</sup>.

To integrate partnership approaches in this stage consultation occurred with the Advisory Group to determine how they would prefer for findings to be presented to them. Findings were synthesised with the Advisory Group through *Yarning*, an Indigenous approach to conversation which involves sharing stories and prioritising Indigenous communication processes<sup>38-40</sup>. Findings were prepared and presented in a range of mediums including slides, charts, graphs, tables, handouts<sup>30</sup>. The approach remained consistent with relationality and prioritising the knowledges of the Advisory Group through a 'workshop' style discussion to make sense of and give meaning to the results and to ensure they were accurate, representative and relevant to lived experiences. The Advisory Group informed strategy for the dissemination of the findings and strategic direction for how best to utilise the findings to influence systems, policy and practice change.

# Implications for public health

Indigenous ways of knowing, being and doing are essential in research with Indigenous populations to ensure that research is of maximum benefit to the community and can be translated into meaningful policy and practice changes which address the significant health inequities experienced. Indigenous methodological approaches are increasingly used in Indigenous research to inform culturally relevant research understandings. There is a long history of research being done "to" rather than "with" Indigenous people, perpetuating negative stereotypes and discourses. Indigenous methodologies create opportunities for strengths-based approaches which prioritise Indigenous ways of knowing, being and doing. From an Indigenous perspective, a scoping review can act as a method of storytelling, understanding and sharing, aiming to translate evidence into culturally relevant and beneficial changes in practice.

The existing scoping review methodology by Levac and colleagues<sup>21</sup> is enhanced by the incorporation of partnership approaches which are culturally relevant, relational, reciprocal and of benefit to populations and communities. Partnership approaches can be implemented to define the question, inform the search, identify relevant studies, determine culturally and contextually relevant variables to chart, inform analysis and plan for the most effective translation of those findings.

Indigenous knowledge can strengthen non-Indigenous research methods across a range of research priorities and for populations who experience significant health inequities.

# **Conclusions**

Aboriginal and Torres Strait Islander communities have a long history with research. At times research has illuminated challenges facing communities while at the same time negatively impacting communities by continuing to create deficit discourses. In addition, research with Aboriginal and Torres Strait Islander communities is often undertaken within a non-Indigenous context utilising non-Indigenous methodologies and methods. The process of decolonising methodologies ensures that Aboriginal and Torres Strait Islander knowledge and expertise inform any research with Aboriginal and Torres Strait Islander communities.

A partnership approach to research with Aboriginal and Torres Strait Islander communities which is grounded in the establishment of mutual trust enables Aboriginal and Torres Strait Islander people to have an integral role in research for their communities<sup>9-13,37</sup>. The skills and knowledge of community are important resources in the research process, and consistent with partnership approaches, the balance of power resides with Aboriginal and Torres Strait

Islander people<sup>9,10,13</sup>. From the outset, a collaborative approach enables knowledge translation, benefit and impact to be planned for accordingly within the review.

Participatory approaches which centre consumer lived experiences in the research process has the potential to enhance the meaning, understanding and interpretation of research benefits for those it is intended to serve. The expansion of the scoping review method to prioritise Indigenous knowledges and expertise as well as the use of a culturally relevant appraisal influences research practice and translation for Aboriginal and Torres Strait Islander communities. Researchers who genuinely integrate the principles of Indigenous methodologies can avoid mistakes of the past, listen to and empower Indigenous communities and researchers to own, control and tell the stories of and for Indigenous people, as they always have.

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[initials removed] implemented the enhanced method and prepared this manuscript. The Advisory Group were integral in the implementation of the method expansion and provided input into and reviewed this manuscript. [initials removed] provided leadership advice and guidance into the methodology, the conceptual design, the implementation of the enhancement and the writing of this manuscript.

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[name removed] Advisory Group

# Authors' information

[name, cultural connection and role removed]. Her research explores Aboriginal and Torres Strait Islander social and emotional wellbeing, including the social determinants of health. [name removed] has expertise in Indigenous methodologies and culturally responsive and ethical ways of working and engaging Aboriginal and Torres Strait Islander people and communities in research.

[name, institute and role removed]. The Platform incorporates a systems view and privileges
Indigenous knowledges to deliver mixed-method inter-disciplinary perspectives which aim to
generate policy and practice-based evidence on the social determinants of health.

[name, cultural connection, institute and role removed]. [name removed] seeks to understand how institutional policies and practices drive health and social inequities experienced by Indigenous populations. Integral to her research is the inclusion of Aboriginal communities in

defining their health and wellbeing and how Indigenous data can be governed in the future to 405 derive greater benefit for the population. 406 407 [name, cultural connection, institute and role removed]. His research is predominantly with 408 Aboriginal and Torres Strait Islander males focused on the utilisation of primary health care 409 services and facilitating the co-design of social and emotional wellbeing programs. 410 411 [name, cultural connection, institute and role removed] over the last 20 years has established 412 an extensive and unique research program focused on chronic disease in vulnerable 413 communities. He leads projects encompassing epidemiology, psychosocial determinants of 414 415 chronic disease, mixed methods health services research in Aboriginal primary care and hospital settings, and randomised controlled trials of pharmacological and non-416 417 pharmacological chronic disease interventions. His work has a particular focus on outlining and overcoming health disparities. 418 419 References 420 1. Wilson S. Research is ceremony: Indigenous research methods. Black Point, Nova 421 Scotia: Fernwood Publishing; 2008. 422 423 2. Walter M, Andersen C. Indigenous Statistics: A Quantitative Research Methodology. 424 Walnut Creek, United States: Routledge; 2013. 425 426 3. Moreton-Robinson A. Towards an Australian Indigenous Women's Standpoint 427 Theory. Australian Feminist Studies. 2013;28(78):331-47. 428

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# Table 1: Scoping Review Methodology – Integrating Indigenous Knowledge

| Stage  | Arksey and<br>O'Malley <sup>19</sup>  | Challenges <sup>21</sup>  | Recommendations <sup>21</sup>  | Integrating Indigenous<br>Knowledge   |
|--|---|---|--|---|
| 1) Partnership   | Consumer and stakeholder involvement to suggest additional references and insights.   | This stage is originally listed as optional, and it is not clear about when, how and why to undertake consultation. | Should be an essential component with a clearly established purpose. Preliminary findings can be used as a foundation for consultation with incorporated opportunities for knowledge transfer and exchange.                      | <ul> <li>A genuine partnership<br/>approach based on<br/>relationships and<br/>collaborative processes<br/>integrated across each<br/>stage, moving beyond<br/>consultation.</li> </ul>             |
| 2) Identifying the research question                         | Clearly defined question provides breadth of coverage to inform subsequent stages.  | Scoping review questions are broad and establishing a purpose is not associated with a framework stage.             | Clear purpose, rationale and intended outcome with defined concept, population and outcomes of interest.   | <ul> <li>Co-production of review<br/>question with a culturally<br/>relevant context, target<br/>population, and<br/>concept/outcome of<br/>interest.</li> </ul>                                    |
| 3) Identifying relevant studies                              | Development of search strategy including search terms, time spans, sources as well as resources available and limitations.                  | Balancing breadth and comprehensiveness of the scoping review with feasibility of resources.                        | Research question and purpose guide the search strategy.   | <ul> <li>Flexible consultations and collaboration with cultural and industry expertise to identify additional studies.</li> <li>Breadth for topics with emerging peer reviewed evidence.</li> </ul> |
| 4) Study<br>selection  | Post hoc inclusion<br>and exclusion<br>based on criteria<br>informed by the<br>research question.   | Misleading – not a linear process and the process for decision making not defined.                                  | Iterative with reviewers meeting at<br>the beginning, mid-point and final<br>stages searching the literature,<br>refining the search strategy, and<br>reviewing articles for inclusion.  | <ul> <li>Co-produced selection criteria.</li> <li>Reviewers with cultural and content knowledge.</li> <li>Culturally grounded study selection.</li> </ul>   |
| 5) Charting<br>the data                                      | A data-charting form is developed and used to extract data from each study.   | The nature and extent of data to extract from included studies requires clarity.                                    | Data charting is collectively developed by the research team with an iterative process to charting updating through the extraction.  | <ul> <li>Co-developed extraction tool.</li> <li>Cultural Appraisal.</li> <li>Culturally relevant and useful data extracted for service provision/policy makers etc.</li> </ul>                      |
| 6) Collating,<br>summarising<br>and reporting<br>the results | Intended to present<br>an overview of all<br>material reviewed<br>and requires a<br>consistent<br>approach to<br>reporting all<br>findings. | Limited detail and the<br>steps are summarised<br>as one framework<br>stage.  | Three distinct steps 1) Analysis including descriptive numerical summary and qualitative thematic 2) Reporting the results as per the intended purpose and 3) Implications of findings for future research, practice and policy. | Collaborative synthesis of<br>findings to ensure<br>accuracy, representative<br>of experiences and have<br>practical utilisation e.g<br>knowledge translation and<br>benefit to community.          |

Adapted from Levac, Colquhoun and Obrien 2010 "Scoping Studies: advancing the methodology"<sup>21</sup>

# APPENDIX 4.2: ABORIGINAL AND TORRES STRAIT ISLANDER QUALITY APPRAISAL TOOL



# The Aboriginal and Torres Strait Islander Quality Appraisal Tool

Appraising research quality from an Aboriginal and Torres Strait Islander perspective

**Companion Document** 

# **ACKNOWLEDGEMENT OF COUNTRY**

We acknowledge and celebrate that Aboriginal and Torres Strait Islander people are the Traditional Custodian of he land, known as Australia. We recognise that Aboriginal and Torres Strait Islander people are the First Peoples of Australia and that within these two distinct cultural groups, there is great cultural diversity.

We acknowledge that SAHMRI is located on the traditional lands of the Kaurna people and pay our respects to the Kaurna people, Elders, past and present, their continuing connection to this land and thriving cultural practices and knowledge.

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**THE ABORIGINAL AND TORRES STRAIT ISLANDER QUALITY APPRAISAL TOOL:** Appraising research quality from an Aboriginal and Torres Strait Islander perspective – Companion Document

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# **DEFINITIONS**

While there are more traditional definitions for the following words and phrases, the definitions provided below are in the context of conducting research with Aboriginal and Torres Strait Islander peoples, families and communities.

#### **BENEFIT**

The benefits of the research must be determined by the Aboriginal and Torres Strait Islander community who are participating in the research. The type of benefit(s) will vary depending on the research and participants involved in the research, but it should be meaningful, appropriate and proportional to participant involvement.

#### **CAPACITY STRENGTHENING**

Aboriginal and Torres Strait Islander peoples and communities are provided training and employment opportunities throughout the research project. At the end of the project, Aboriginal and Torres Strait Islander peoples and communities should have additional skills, experience and knowledge about how to negotiate, assist with, implement and lead future research.

#### **COMMUNITY**

A group of people living in the same place or belonging to the same language group or having a particular characteristic in common, at an organisational, local, state or national level.

#### **CONTROL**

The power to exert, influence or direct people's behaviour or the course of research process and outcomes.

# **CULTURAL AND INTELLECTUAL PROPERTY**

The rights of Aboriginal and Torres Strait Islander peoples, community or language group to share, access, control, maintain and grow their cultural and intellectual heritage. Cultural and intellectual property incorporates the tangible and intangible, including knowledge, artefacts and expression. It incorporates all aspects of knowledge (sciences, plant and animal knowledge, stories, designs and symbols, ritual knowledge), artefacts (arts, crafts, weapons, tools and technology), expression (ceremonies, dance and song) and human remains, and includes the secret and sacred. These rights are perpetual and form a living heritage, reinterpreted by each new generation [7]. It used to inform or generated from the research.

#### **FAMILY**

A group of two or more people, either immediate or extended family, who identify as a family. Governance – An existing or established group or organisation that enables and monitors the implementation of community protocols, provides the relevant cultural and contextual knowledge to inform the research and enables Aboriginal and Torres Strait Islander peoples to have authority over the research throughout the research process.

# **INDIGENOUS RESEARCH PARADIGM**

Reflects Aboriginal and/or Torres Strait Islander ways of knowing, being and doing [4, 8, 9] and is based on the lived experiences and knowledges of Aboriginal and Torres Strait Islander peoples, which informs and quides research processes.

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# CENTRE OF RESEARCH EXCELLENCE IN ABORIGINAL CHRONIC DISEASE KNOWLEDGE TRANSLATION AND EXCHANGE

The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE), is a National Health and Medical Research Council (NHMRC)-funded research program dedicated to improving service delivery and health outcomes for Aboriginal and Torres Strait Islander peoples, with a particular focus on chronic disease. The Centre is a collaborative enterprise between:

- National Aboriginal Community Controlled Health Organisation (NACCHO)
- Wardliparingga Aboriginal Research Unit, South Australian Health and Medical Research Institute (SAHMRI);
- University of Adelaide School of Public Health and Joanna Briggs Institute (University of Adelaide)

CREATE aims to assist the Aboriginal health sector to improve the coverage and appropriateness of their services and care through the synthesis of using new and existing knowledge (published and unpublished literature) about best practice chronic disease prevention and management as well as sustainable primary health care funding and service delivery models.

Objectives:

- To use existing evidence and, where necessary, develop and collate new evidence to inform guidelines, policies and/or other tools focused on improving care and outcomes experienced by Aboriginal and Torres Strait Islander peoples with, or at risk of developing, a chronic disease.
- To strengthen the capacity of Aboriginal and Torres Strait Islander health service providers and researchers to conduct and use evidence to improve health outcomes.

# **PREAMBLE**

# What is the Aboriginal and Torres Strait Islander Quality Appraisal Tool?

The *Aboriginal and Torres Strait Islander Quality Appraisal Tool* is a set of fourteen criteria for appraising the quality of research in Australian settings with Aboriginal and Torres Strait Islander peoples, families and communities through an Aboriginal and Torres Strait Islander lens. Aboriginal and Torres Strait Islander peoples' values and ethics have informed the criteria in the tool with the intent to achieve appropriate, high quality and relevant health research that benefits Aboriginal and Torres Strait Islander peoples.

# What is the Aboriginal and Torres Strait Islander Quality Appraisal Tool Companion Document?

The *Aboriginal and Torres Strait Islander Quality Appraisal Tool Companion Document* provides users with guidance on how to interpret and assess research articles using the *Aboriginal and Torres Strait Islander Quality Appraisal Tool.* 

# What is the purpose of the Quality Appraisal tool?

The *Aboriginal and Torres Strait Islander Quality Appraisal Tool* is designed to appraise the quality of studies, primarily as part of the systematic review process. It has been designed to consider studies in Australian settings with Aboriginal and Torres Strait Islander peoples, families and communities. Other purposes for the *Aboriginal and Torres Strait Islander Quality Appraisal Tool* include: 1) editors of journals that include studies involving Aboriginal and Torres Strait Islander participants; 2) reviewers of journal articles documenting Aboriginal and Torres Strait Islander research 3) funders who review proposals for research studies involving Aboriginal and Torres Strait Islander participants; and 4) researchers planning to carry out research with Aboriginal and Torres Strait Islander peoples. The tool is designed to be used in addition to other critical appraisal tools used in systematic reviews.

# Why do we need the Aboriginal and Torres Strait Islander Quality Appraisal Tool?

The history of colonisation of Aboriginal and Torres Strait Islander peoples in Australia is reflected in the record of research with Australia's culturally diverse Aboriginal and Torres Strait Islander peoples.[1-3] Health and medical research in particular, has a long record of researchers gathering information from Aboriginal and Torres Strait Islander peoples without consulting and gaining approval from relevant Aboriginal and Torres Strait Islander peoples and organisations.[2] Rather than working in partnership with Aboriginal and Torres Strait Islander research participants and being guided by Aboriginal and Torres Strait Islander peoples, researchers have tended to treat participants as research objects.[2] Western research values and Western ontology, epistemology and axiology have governed the Western methodologies that have dominated health research in Australia.[2, 4] Informed by Western research values, researchers have defined the objectives of research without considering the research participants and their communities' needs. Yet Western research methodologies are fundamentally different from those of Aboriginal and Torres Strait Islander peoples, whose ways of knowing, being and doing are based on lived experiences

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and knowledge as Aboriginal and Torres Strait Islander peoples. Reliance on Western ways of doing health research in Australian settings with Aboriginal and Torres Strait Islander participants has exploited and harmed Aboriginal and Torres Strait Islander peoples and prevented research from being an effective tool to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples. Recently, more and more research is beginning to take a strength-based approach, ensuring research is conducted with and for the benefit of Aboriginal and Torres Strait Islander peoples.

# How was the Aboriginal and Torres Strait Islander Quality Appraisal Tool Developed?

Senior Aboriginal and Torres Strait Islander health researchers, together with ethicists and systematic review experts, developed the tool and companion document over a three-year period, using a combination of literature review and interactive group work. A modified Delphi method was used to assess the face validity, reliability and feasibility of the tool. An independent Australian panel comprising senior Aboriginal and Torres Strait Islander researchers critiqued the tool and made recommendations for improvements. Systematic reviewers independent of the development then trialed the tool for reliability and feasibility.

# How to use the Aboriginal and Torres Strait Islander Quality Appraisal Tool?

The *Aboriginal and Torres Strait Islander Quality Appraisal Tool* should be applied to articles that involve Aboriginal and Torres Strait Islander peoples, families and communities. The *Aboriginal and Torres Strait Islander Quality Appraisal Tool* should be used in conjunction with existing tools to critically appraise research. This will enable a more comprehensive assessment of study quality and value by including review through an Aboriginal and Torres Islander lens.

Each of the 14 criteria in the *Aboriginal and Torres Strait Islander Quality Appraisal Tool* should be used to assess evidence contained within the article. The practical examples included in this Companion Document illustrate good practice in relation to each criterion and should be used as a guide. In addition, separate correspondence that has been specifically sought for clarification from the author should also be considered in assessing quality.

If the article provides adequate evidence to meet the criteria, "Yes" should be marked. If the criteria are partially met, "Partial" should be marked. If there is no evidence to meet the criteria, "No" should marked. If it is unclear to elicit from the article then "Unclear" should be marked.

The appraisal of each paper may be summarized by the number of "Yes", "No", "Partial" and "Unclear", and or displayed in a table. Further discussion on the appraisal may also be provided. The *Aboriginal and Torres Strait Islander Quality Appraisal Tool* should not be used to exclude articles.

N.B. – Meeting all the criteria within the *Aboriginal and Torres Strait Islander Quality Appraisal Tool* does not negate the need to ensure appropriate ethics approval has been received prior to the commencement of any study. Research with Aboriginal and Torres Strait Islander peoples, communities and organisations must receive ethics approval from an Aboriginal Human Research Ethics Committee. This ensures that the research aligns with ethical guidelines such as the National Health and Medical Research Council Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research[5] and the National Statement on Ethical Conduct in Human Research[6] and has demonstrated that appropriate considerations have been given to the conception, design and conduct of research with Aboriginal and Torres Strait Islander communities.

# ABORIGINAL AND TORRES STRAIT ISLANDER QUALITY APPRAISAL TOOL

### ABORIGINAL AND TORRES STRAIT ISLANDER QUALITY APPRAISAL TOOL



| Article citation: _ | Date: |
|---------------------|-------|
|                     |       |

| Reviewer's name: |  |  |
|------------------|--|--|
|                  |  |  |

Answer either "Yes", "Partially", "No" or "Unclear" to each question

| Question  | Yes | Partially | No | Unclear |
|---|-----|-----------|----|---------|
| 1. Did the research respond to a need or priority determined by the community?  |     | 0         | 0  | 0       |
| 2. Was community consultation and engagement appropriately inclusive?   | 0   |           |    |         |
| 3. Did the research have Aboriginal and Torres Strait Islander research leadership?   | 0   |           |    | 0       |
| 4. Did the research have Aboriginal and Torres Strait Islander governance?  | 0   | 0         | 0  |         |
| 5. Were local community protocols respected and followed?   | 0   | 0         | 0  | 0       |
| 6. Did the researchers negotiate agreements in regards to rights of access to existing Aboriginal and Torres Strait Islander peoples' intellectual and cultural property?           | 0   | 0         | 0  | 0       |
| 7. Did the researchers negotiate agreements to protect the intellectual and cultural property of Aboriginal and Torres Strait Islander peoples <u>created</u> through the research? | 0   | 0         | 0  |         |
| 8. Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?   | 0   | 0         | 0  | 0       |
| 9. Was the research guided by an Indigenous research paradigm?  | 0   | 0         | 0  | 0       |
| 10. Does the research take a strength based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?                  | 0   | 0         | 0  | 0       |
| 11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?   | 0   | 0         | 0  | 0       |
| 12. Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?  | 0   | 0         | 0  | 0       |
| 13. Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?  | 0   | 0         | 0  | 0       |
| 14. Did everyone involved in the research have opportunities to learn from each other?  | 0   | 0         | 0  | 0       |

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### Did the research respond to a need or priority determined by the community?

Research effort is in response to priorities arising from, negotiated with and endorsed by the Aboriginal and Torres Strait Islander community affected by the research. This will ensure the research is relevant, and improve its acceptability and accountability to the Aboriginal and Torres Strait Islander community who will be impacted.

Things to look for in written documentation:

- An Aboriginal or Torres Strait Islander community, group or organisation approached the researcher or research group with a research question or project.
- An Aboriginal or Torres Strait Islander community, group or organisation were involved in identifying and setting priorities.
- Priorities were identified through national, state or local documents, such as policies, plans and strategies e.g. National Indigenous Reform Agreement, The National Aboriginal and Torres Strait Islander Health Plan.
- Emerging issues that impact on Aboriginal and Torres Strait Islander peoples, families and communities both politically and socially are recognised by the communities themselves.

#### **PRACTICAL EXAMPLES**

An Aboriginal health organisation approached researchers with an idea for a research project on sexual health screening within their community.

A community forum was held to identify and set priorities about an emerging issue faced by an Aboriginal community.

At a national conference on Aboriginal and Torres Strait Islander mental health, participants called upon governments to address the prevalence of suicide among Aboriginal and Torres Strait Islander peoples.

An Aboriginal community, group or organisations has been advocating for cheaper and healthier food and drink items at their local community store.

### Was community consultation and engagement appropriately inclusive?

Significant diversity exists within and across Aboriginal and Torres Strait Islander communities, therefore generalisations cannot be made. Engagement and inclusion of a range of existing organisations, groups and governance structures within the local community prior to and throughout the research is appropriate and good practice.

Things to look for in the written documentation:

- Evidence that organisations representing the participants were consulted prior to starting the research.
- Evidence that researchers identified and consulted a diverse range of relevant local community organisations and groups to cover the range of interests and needs of the research participants.
- Statements by authors about enhancement, a change or adjustment of the question, method, interpretation of results or knowledge translation based on consultation with the community.

#### **PRACTICAL EXAMPLES**

Prior to starting a large cohort study, consultation occurred with every Aboriginal community throughout the state. A second round of consultation occurred before the start of each community site and the recruitment of participants. It was during the initial consultations that it became apparent that the original name of the study had no meaning to Aboriginal peoples and therefore the name was changed to reflect what the study was investigating.

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# Did the research have Aboriginal and Torres Strait Islander research leadership?

It is expected that research with Aboriginal and Torres Strait Islander peoples, families and communities has Aboriginal and Torres Strait Islander leadership. Ideally, an Aboriginal and Torres Strait Islander person(s) would be a principal investigator or, at the very least, be members of the research leadership team. Having Aboriginal and Torres Strait Islander persons as principal or senior investigators ensures that Aboriginal and Torres Strait Islander peoples' ways of knowing, being and doing are reflected throughout the research project, and that the research aligns with the National Health and Medical Research Council Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. [5]

Things to look for in the written documentation:

- One or more of the Chief Investigators is an Aboriginal and/or Torres Strait Islander person.
- An Aboriginal and/or Torres Strait Islander person or group of people led the research implementation process.
- The research team consists of Aboriginal and/or Torres Strait Islander people(s) who are responsible to the Aboriginal or Torres Strait Islander community for the integrity of the research and research output with the authority to make decisions; they may be referred to as senior researchers or senior Aboriginal leaders.

#### **PRACTICAL EXAMPLES**

One or more Aboriginal researchers are Chief Investigators of a Centre of Research Excellence. A group of Aboriginal and Torres Strait Islander researchers led the development of an appraisal tool which is used to assess the quality of research involving Aboriginal and Torres Strait Islander peoples.

A research project investigating the benefits of dietary supplements within the Aboriginal and Torres Strait Islander populations is administered by an Aboriginal Research Nurse.

# Did the research have Aboriginal and Torres Strait Islander governance?

Aboriginal and Torres Strait Islander governance enables authority over the research throughout the research process. Aboriginal and/or Torres Strait Islander governance structures ensure community protocols are followed and enable relevant cultural and contextual knowledge to inform the research. Researchers must work together with relevant Aboriginal and/or Torres Strait Islander peoples throughout the research process, and with a relevant existing governance structure or establish one or more Aboriginal and Torres Strait Islander governance structure(s).

Things to look for in written documentation:

- Evidence that a group of Aboriginal and/or Torres Strait Islander peoples informed, guided, monitored and had some degree of control over the research throughout the research process, including in planning stages.
- Evidence that the researchers reported to the group of Aboriginal and/or Torres Strait Islander peoples, that their guidance informed the direction of the project, and that the governance structure had authority to make decisions.

#### PRACTICAL EXAMPLES

A community reference group was established with members representing each of the communities involved in the research project. The community reference group guided and had authority over the research throughout the research process to ensure the research was conducted appropriately, informed the analysis and interpretation and ensured the research outcomes were meaningful.

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### Were local community protocols respected and followed?

Community obligations and protocols will always take precedence over formal business such as research. In the case of unexpected events, community leaders and members will be required to meet their cultural obligations which may impact upon the research timelines and outcomes. Protocols may differ between local communities and it is the responsibility of researchers to familiarise themselves with and to follow the appropriate local protocols of the community before engagement commences. This will reduce the risk of the researcher breaching local community protocols.

Things to look for in written documentation:

- Evidence that local protocols were followed to access appropriate research participants, for example females for women's business research.
- Evidence that timing of the research was changed to respect significant community events, for example the need for community members to participate in sorry business.
- Evidence that the researchers aligned their data collection approach to ensure that cultural protocols of the community were respected.
- Evidence that interpreters were used to ensure community protocol was adhered to where English is not the first language.

#### **PRACTICAL EXAMPLES**

Cultural knowledge was shared with the researcher to inform the research; however, it was not included in any research outcomes as it was not appropriate to or approved by the leaders of the community.

Due to significant unplanned event in the community there was a delay in the research.

### Did the researchers negotiate agreements in regards to rights of access to existing Aboriginal and Torres Strait Islander peoples' intellectual and cultural property?

In all research projects a formal agreement will be negotiated, outlining the rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property, including acknowledging the contribution of Aboriginal and Torres Strait Islander peoples. Whilst Memoranda of Understanding (MOUs) are commonly used to document agreements about the rights and responsibilities of the partners in research, a legally binding agreement is preferred, as this is better able to protect and promote the interests of Aboriginal and Torres Strait Islander peoples. The agreement will clarify the roles and responsibilities of the researchers and community members in the research, describe the benefits to the community as determined by community, including resource sharing and training to be delivered as part of the research. It will also describe the rights of access to Aboriginal and Torres Strait Islander peoples' intellectual and cultural property and data ownership.

Things to look for in written documentation:

A statement in the article that a legally binding contract to protect the intellectual and cultural property of the participants and community involved was developed and negotiated between the researcher(s) and the responsible community organisations and individuals prior to the research.

#### **PRACTICAL EXAMPLES**

A Collaborative Research Agreement was developed in partnership between the research institute and the local community board. The Agreement outlined the roles and responsibilities between the two organisations, the sharing of resources, consultation and engagement, cultural protocols, research outcomes, research benefits for the community, employment and training opportunities, timeframes and existing intellectual and cultural property rights. A group of researchers approaches Aboriginal Community Controlled Health Organisations because they wish to document how programs are funded and implemented to address the social determinants of health. The group sought ethics approval to ensure that the research findings deliver benefits for the sector and the communities.

A researcher writing a biography of an Aboriginal artist negotiated an agreement with the artist and their community.

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### Did the researchers negotiate agreements to protect the intellectual and cultural property of Aboriginal and Torres Strait Islander peoples created through the research?

Knowledge created through research must remain the intellectual property of Aboriginal and Torres Strait Islander contributors, and all published material must abide by the National Health and Medical Research Council Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.[5] Researchers must appropriately acknowledge, in research outputs, the contributions of the Aboriginal and Torres Strait Islander researchers, research participants, governance structures, and Aboriginal and Torres Strait Islander peoples in the generation of new knowledge.

Things to look for in written documentation:

- Evidence that the researchers understand that the knowledge generated by the research remains the intellectual property of the Aboriginal and Torres Strait Islander contributors to the research.
- A statement in the article that the knowledge generated by the research is the intellectual property of Aboriginal and Torres Strait Islander peoples involved in the research.

#### **PRACTICAL EXAMPLES**

A Collaborative Research Agreement was developed and outlined the details for the arrangements of the creation of new knowledge and intellectual property generated from the research, and the ongoing management and use of the knowledge and intellectual property. A series of case studies with Aboriginal Community Controlled Health Organisations are prepared. The findings from the research belong to the ACCHO and approval is sought from the ACCHO to publish the findings.

# Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?

Aboriginal and Torres Strait Islander peoples, families and communities must have control over the respectful and appropriate collection and management of all biological and non-biological research materials. Local Aboriginal and Torres Strait Islander communities remain the owners of the data they provide as research participants.

Things to look for in written documentation:

- Development of a protocol in partnership with Aboriginal and Torres Strait Islander peoples for the respectful and appropriate collection and management of all biological and non-biological research materials.
- The consent processes give the participants control over how their data and samples will be managed.
- Evidence that participant consent is specific to the project and not for extended or unspecified uses.

#### **PRACTICAL EXAMPLES**

Protocols relating to the collection and/or use, management and storage of data were developed by or in partnership with Aboriginal and/or Torres Strait Islander people and adhered to by researchers.

A community withheld information relating to private cultural knowledge and practices because it thought that the information might harm the community due to its political sensitivity. This was reported as an aspect of the research process that was cancelled due to advice from community leaders.

Aboriginal and Torres Strait Islander research leadership contributed to Aboriginal and Torres Strait Islander control of data.

The public findings from the study included a statement about not publishing, withholding, withdrawing or destroying data (this may be in the form of biological samples or health information).

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# Was the research guided by an Indigenous research paradigm?

An Aboriginal or Torres Strait Islander research paradigm reflects Aboriginal and/or Torres Strait Islander ways of knowing, being and doing [4, 8, 9] and is based on the lived experiences and knowledges of Aboriginal and Torres Strait Islander peoples. The research methodology and methods must reflect the community values, priorities and perspectives of research participants and their communities.

Diversity exists within and across Aboriginal and Torres Strait Islander communities in Australia. It is the responsibility of the researchers to ensure that the diversity is understood, protected, respected and reflected within the research process. This unique and local knowledge is critical to ensure that the data collection, analysis and interpretation of research results include all the issues that are important for valid conclusions and relevant recommendations.

Things to look for in written documentation:

- Evidence that an Indigenous research paradigm was used, with a clear description of how it reflects Aboriginal and Torres Strait Islander ways of knowing, being and doing.
- Acknowledgment that health and wellbeing are complex and interconnected and require multiple research methods.
- Evidence that the ways of knowing, being and doing of the Aboriginal and Torres Strait Islander peoples' informed research processes including engagement, conceptualisation, implementation, interpretation and dissemination of research findings.
- A description of steps taken by the researchers, prior to and during the research to understand the perspectives of relevant local cultural and contextual experts, (for example Elders, Board members, local community groups), and how this knowledge was integral in the research.

#### **PRACTICAL EXAMPLES**

'This study used an exploratory, descriptive design, guided by an Indigenous research approach. The research question being asked, the participants being interviewed, as well as one of the Chief Investigators identifying as being Aboriginal and/or Torres Strait Islander, demanded the use of a research approach that removes the voice of the coloniser and places value on Indigenous knowledge. The research team believed it was important to privilege Indigenous voices and Indigenous lives.'[10]

An Aboriginal female researcher using a mixed-method design to assess prevalence and experiences of asthma amongst Aboriginal youth identified herself as a member of the Aboriginal community, and described how being part of this community shaped her research methodology.

The use of state and national level data sets to report and monitor health inequalities at a local level, with the local community proposing research questions, informing analysis and interpreting results.

# Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?

Researchers and research practices must build on Aboriginal and Torres Strait Islander strengths and resilience. Research must contribute to improved health, social and economic outcomes experienced by Aboriginal and Torres Strait Islander peoples, families and communities. Researchers and research processes must avoid practices which have been harmful to Aboriginal and Torres Strait Islander peoples, families and communities.

Things to look for in written documentation:

- Evidence that the researchers acknowledge past harms, understand that imposition of Western values and perspectives is detrimental to Aboriginal and Torres Strait Islander peoples' health outcomes and demonstrate their efforts not to contribute to past practices.
- Research takes a strengths-based approach by identifying positive attributes such as resilience as opposed to risk factors that are already established.
- Evidence that the research identified and built upon strengths in the local community of the research participants and/or strengths of other Aboriginal and Torres Strait Islander communities.

#### **PRACTICAL EXAMPLES**

The researchers acknowledged that in certain circumstances past research practices have done more harm than good and have impacted negatively on the health and wellbeing of Aboriginal and Torres Strait Islander peoples, families and their communities.

The research question on mental health was altered to take a strengths-based approach and to avoid a deficit approach.

Findings or a research project outlined the protective factors of maintaining connection to Country that contribute to positive health and wellbeing outcomes.

Research offers solutions that have been informed by Aboriginal and Torres Strait Islander community members and the findings of the research.

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# Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?

Dissemination of research processes and/or findings to relevant individuals and organisations to contribute to sustainable improvements in policy and/or practice is essential and requires planning at the outset. Research on Aboriginal and Torres Strait Islander priorities done in partnership with the community is more likely to successfully influence change.

Things to look for in written documentation:

- Evidence of a comprehensive knowledge translation plan which has been implemented.
- Evidence that the research has resulted in policy development and/or informed practice.
- Evidence that skills transferred to Aboriginal and/or Torres Strait Islander peoples through the research are likely to lead to changes in the way health policy is formulated, the content of health policies, health service delivery and/or sustainable improvements in the health of Aboriginal and Torres Strait Islander peoples.

#### **PRACTICAL EXAMPLES**

Research governed by an Aboriginal Reference Group whose role includes interpreting both epidemiological and qualitative findings was used to inform the development of a state-wide Aboriginal policy document and patient reported outcome measure, both of which are used to inform clinical care for Aboriginal peoples.

### Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?

Research must produce meaningful benefits for Aboriginal and Torres Strait Islander peoples and their communities. It must do more than merely describe the issues. The benefits of the research must be determined by the Aboriginal and Torres Strait Islander community who are participating in the research. Where possible, there should be ongoing benefits to the participants and communities from the research.

Things to look for in written documentation:

- Evidence that research provided a service "No survey without service" to the Aboriginal and Torres Strait Islander participants.
- Evidence that the research provided a resource for the local Aboriginal and Torres Strait community where the research was being done.
- Evidence that the research outcomes benefited Aboriginal and Torres Strait Islander peoples belonging to other communities, in addition to the one(s) of the local research participants.
- Authors reported the short-, medium- and long-term benefits (as identified by the community) the research delivered to Aboriginal and Torres Strait Islander people and or the local community.

#### **PRACTICAL EXAMPLES**

A cohort study involving the delivering of a screening program provided individuals with an immediate clinical service, treated treatable conditions and facilitated on-going care through clinical integration.

A research project focusing on environmental health resulted in a water fountain being installed in three community parks.

A tool was developed and subsequently used to help guide future research with Aboriginal and Torres Strait Islander peoples in a culturally responsive and safe way.

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# Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?

Aboriginal and Torres Strait Islander peoples should be trained and employed throughout the research project. Investing in Aboriginal and Torres Strait Islander peoples who are members of the participating community/s is essential to improving their health and wellbeing. At the conclusion of the research project, local Aboriginal and Torres Strait Islander peoples should have additional skills, experience and knowledge about how to negotiate, assist with, implement and lead future research. These strengthened attributes will contribute to the advancement of local communities and the broader Aboriginal and Torres Strait Islander community in Australia.

Things to look for in written documentation:

- Evidence of employment of Aboriginal and Torres Strait Islander peoples who are members of the participating community where the research was being done.
- Evidence that Aboriginal and Torres Strait Islander peoples employed in the research continue with other research roles.
- Evidence of formal and/or informal training of Aboriginal and Torres Strait Islander peoples delivered as part of the research process.
- Evidence that local businesses owned by and/or employing Aboriginal and Torres Strait Islander peoples were used to provide services for research activities.

#### **PRACTICAL EXAMPLES**

Local Aboriginal and Torres Strait Islander Health Workers were seconded part time to work as research officers on an 18-month project whilst being supported through a certified introduction to research course.

A local Aboriginal artist was commissioned to develop the research project logo. A local business owned and operated by Aboriginal people was hired to cater for a research event.

The research itself focused on capacity strengthening; for example, Aboriginal and Torres Strait Islander people were supported through research scholarships to complete an Honours or Masters by research or PhD qualification.

An existing Aboriginal women's group partnered with a research team on a family resilience project. Through the project the Aboriginal women's group linked with other state and national community groups and built on their research track record.

### Did everyone involved in the research have opportunities to learn from each other?

There should be two-way learning through the research process that encompasses capacity strengthening of Aboriginal and Torres Strait Islander peoples, families and communities and non-Indigenous and Aboriginal and Torres Strait Islander researchers. Aboriginal and Torres Strait Islander peoples, families and communities should have the opportunity to learn about all components of the research process. Non-Indigenous researchers and their research communities should be able to learn from research with Aboriginal and Torres Strait Islander researchers and participants about their culture, and ways of knowing, being and doing.

Things to look for in written documentation:

- Evidence of equal partnership between Aboriginal and Torres Strait Islander researchers and non-Indigenous researchers.
- The employment of Aboriginal and Torres Strait Islander peoples on the research project, as researchers, research assistants, culture brokers and/or in research training roles.
- Researchers spent time at the beginning of the research process with the community to understand community protocols, the culture of participants and shared their knowledge about the research process.
- Researchers presented the findings back to the participants and the community at the end of the research project.

#### **PRACTICAL EXAMPLES**

A cross sectional population-based study being led by a non-Indigenous principal researcher with the aim of investigating Aboriginal women's health undertook extensive pre-planning consultation, which resulted in the establishment of an Aboriginal Advisory Group to guide the conduct of consultations and development of the research. The Aboriginal Advisory Group were active partners in the research from its inception and provided leadership, guidance and direction to the project and were all investigators of the study in their own right. The principal researcher has grown in their capacity to conduct research with Aboriginal communities the right way, as a result of this experience.

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- 2. Laycock, A., et al., *Researching Indigenous Health: A practical guide for researchers*. 2011, The Lowitja Institute: Melbourne.
- 3. Rigney, L.-I., *Internationalization of an Indigenous Anticolonial Cultural Critique of Research Methodologies: A Guide to Indigenist Research Methodology and Its Principles.* Wicazo Sa Review, 1999. **14**(2): p. 109-121.
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- 5. National Health and Medical Research Council, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. 2003, Commonwealth of Australia: Canberra.
- 6. National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research*. 2007 (Updated May 2015), Commonwealth of Australia: Canberra.
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- 8. Kovach, M.E., *Indigenous methodologies: characteristics, conversations, and contexts* 2010, Toronto: University of Toronto Press.
- 9. Wilson, S., Research is ceremony: Indigenous research methods. 2008, Winnipeg: Fernwood.
- 10. Kelly, J., et al., 'She knows how we feel': Australian Aboriginal and Torres Strait Islander childbearing women's experience of Continuity of Care with an Australian Aboriginal and Torres Strait Islander midwifery student. Women and Birth, 2014. **27**(3): p. 157-162.





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# APPENDIX 4.3: SUMMARY OF PROGRAMS WHICH ADDRESS THE SOCIAL DETERMINANTS OF HEALTH

| Reference  | Program<br>Name   | Program Summary   | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|--|---|---|---|---------------------------|----------|----------|----------|----------------------|
| Alperstein, G & Dyer, CS 2012, 'The development and implementation of a strategic framework to improve Aboriginal child development and wellbeing in far west NSW: a collaborative approach', New South Wales Public Health Bulletin, vol. 23, no. 3-4, pp. 73-76.   | Maari Ma<br>'Healthy Start'<br>program  | Maari Ma 'Healthy Start' program provides a population based approach to improving infant and child wellbeing. Multi-disciplinary teams of midwives, child and family nurses, primary health and Aboriginal health workers implement a home visiting and clinic based schedule from the ante-natal period to school entry. A collaborative approach working with agencies and organisations influencing the social determinants of health, particularly early childhood education and care. | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Education                 |          | x        |          |                      |
| ARDS Aboriginal Corporation, 2018, 'An ARDS approach to family violence: ARDS Family Violence project 2015-2018: final report'.  | ARDS Family<br>Violence<br>Project  | Recognising the role of social-economic disadvantage and social stressors the project through a series of workshops with Yolngu aimed to increase awareness and discussion of family violence, empower and support to consolidating traditional structures that protect families and increase understanding of the services available to provide support.   | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | No Primary<br>Determinant | x        |          |          |                      |
| Askew DA, TS, Schluter PJ, Rogers L, Egert S, Potter N, Hayman NE, Cass A, Brown A. 2015, Investigating the feasibility, acceptability and appropriateness of outreach case management in an urban Aboriginal and Torres Strait Islander primary health care service: Report prepared for the Australian Primary Health Care Research Institute, Canberra. | Home-based Outreach case Management of chronic disease Exploratory (HOME) Study | The HOME study provided a home-based case management model of patient centred multidisciplinary care for Aboriginal and Torres Strait Islander people with complex chronic disease.  The study provided comprehensive needs assessment with each participant and ensured that the health and social care systems met the identified needs of participants and supported them to achieve their goals.  | State<br>Government   | Health<br>System          |          | x        | x        |                      |

| Reference   | Program<br>Name  | Program Summary  | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|--|--|---|---------------------------|----------|----------|----------|----------------------|
| Bertilone, C & McEvoy, S 2015, 'Success in Closing the Gap: favourable neonatal outcomes in a metropolitan Aboriginal Maternity Group Practice Program', Medical Journal of Australia, vol. 203, no. 6, pp. 262.e261-267.   | Aboriginal<br>Maternity<br>Group<br>Practice<br>Program<br>(AMGPP) | AMGPP aimed to improve access to maternity services. Aboriginal Health Officers, Aboriginal grandmothers and midwives worked together to deliver culturally secure care. The program focus was "early access to antenatal care, employment of Aboriginal staff and holistic care including awareness of the social determinants of health".  | State<br>Government   | No Primary<br>Determinant |          | x        |          |                      |
| Biggs, K, Walsh, J & Ooi, C 2016, 'Deadly Liver Mob: opening the door - improving sexual health pathways for Aboriginal people in Western Sydney', Sexual Health, vol. 13, no. 5, pp. 457-464.  | Deadly Liver<br>Mob  | An incentive-based health promotion intervention for Aboriginal people recognising the barriers of accessing services, including financial barriers. The Aboriginal sexual health worker or the Aboriginal NSP Hepatitis C project officer engage Aboriginal people attending the NSP (needle syringe program). The program delivers incentivised education sessions and screenings for STI/BBV. | State<br>Government   | Income                    | х        |          |          |                      |
| Black, AP, Vally, H, Morris, PS, Daniel, M, Esterman, AJ, Smith, FE & O'Dea, K 2013, 'Health outcomes of a subsidised fruit and vegetable program for Aboriginal children in northern New South Wales', Medical Journal of Australia, vol. 199, no. 1, pp. 46-50. | Fruit and<br>Vegetable<br>Subsidy<br>Program                       | The fruit and vegetable subsidy program for low income families as a strategy to improve socioeconomic inequalities in dietary intake.  The program combines annual health assessments with receiving a weekly box of subsided fruits and vegetables for 12 months.  Recipes, practical cooking and nutrition educations are provided by dietitians.   | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Income                    |          | x        |          |                      |

| Reference   | Program<br>Name  | Program Summary   | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|--|---|---|---------------------------|----------|----------|----------|----------------------|
| Blignault, I, Haswell, M & Pulver, LJ 2016,<br>'The value of partnerships: lessons from a multi-site evaluation of a national social and emotional wellbeing program for Indigenous youth', Australian and New Zealand Journal of Public Health, vol. 40, no. S1, pp. S53-S58.  | SAM Our Way  | SAM Our Way aims to improve the social and emotional wellbeing of young Aboriginal and Torres Strait Islander people (16-26yo). There is a focus on depression, anxiety, violence and alcohol and other drug problems. The program engages young people and strengthens community and stakeholder responses through a range of program activities, particularly engaging with education partners. | Non<br>Government<br>Organisation                               | No Primary<br>Determinant | x        |          |          |                      |
| Brown, C, Laws, C, Leonard, D, Campbell, S, Merone, L, Hammond, M, Thompson, K, Canuto, K & Brimblecombe, J 2019, 'Healthy Choice Rewards: A Feasibility Trial of Incentives to Influence Consumer Food Choices in a Remote Australian Aboriginal Community', International Journal of Environmental Research & Public Health [Electronic Resource], vol. 16, no. 1, p. 03. | Healthy<br>Choice<br>Rewards<br>Program                    | Healthy Choice Rewards program provided store voucher incentives to promote fruit and vegetable purchasing in a remote Aboriginal community. The program was delivered in a low income area and healthy foods cost more than urban areas to promote food choices which contribute to improved health outcomes.  | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Income                    |          | x        |          |                      |
| Burgess, PM, A. Bailie, R. 2008 Beyond the mainstream - health gains in remote Aboriginal communities.  | Arnhem Land -<br>Healthy<br>country,<br>healthy<br>people' | The Health country, healthy people study investigated the outcomes associated with 'caring for country' practices.  | Undetermined  | Cultural<br>Connection    |          | x        | x        |                      |

| Reference   | Program<br>Name   | Program Summary   | Context             | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|---|---|---------------------|---------------------------|----------|----------|----------|----------------------|
| Conway, J, Lawn, S, Crail, S & McDonald, S 2018, 'Indigenous patient experiences of returning to country: a qualitative evaluation on the Country Health SA Dialysis bus', BMC Health Services Research, vol. 18, no. 1, p. 1010.   | Country<br>Health SA<br>Dialysis Bus                      | The South Australian mobile dialysis truck is a service which visits remote communities, allowing patients to have dialysis "on country" reuniting them with their friends and family and providing a chance to take part it cultural activities.   | State<br>Government | Cultural<br>Connection    |          | x        | x        | х                    |
| Cresp, R, Clarke, K, McAuley, KE, McAullay, D, Moylan, CA, Peter, S, Chaney, GM, Cook, A & Edmond, KM 2016, 'Effectiveness of the Koorliny Moort out-of-hospital health care program for Aboriginal and Torres Strait Islander children in Western Australia', Medical Journal of Australia, vol. 204, no. 5, pp. 1971e-1977. | Koorliny<br>Moort<br>Program                              | The Koorliny Moort program through a multi-<br>disciplinary approach provided nurse led care<br>coordination. Assistance included coordinating<br>appointments to facilitate increased access,<br>discharge planning, health advice, social<br>cultural and family support, and telehealth<br>services. Outreach care included social work,<br>nursing and paediatrician follow up.   | State<br>Government | Health<br>System          | x        |          |          |                      |
| Cuesta-Briand, B, Bessarab, D, Shahid, S & Thompson, SC 2016, "Connecting tracks': exploring the roles of an Aboriginal women's cancer support network', Health & Social Care in the Community, vol. 24, no. 6, pp. 779-788.  | The Aboriginal<br>Women's<br>Cancer<br>Support<br>Network | The Aboriginal Women's cancer support network provided support to women affected by cancer, including women undergoing cancer treatment, cancer survivors and carers.  Fortnightly meetings were held a community based venue supported by a coordinator and peer volunteers to facilitate access to services, foster social interaction, provide a culturally safe space and build relationships with services and agencies. | Undetermined        | No Primary<br>Determinant | X        |          |          |                      |

| Reference   | Program<br>Name                 | Program Summary   | Context             | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|---------------------------------|---|---------------------|---------------------------|----------|----------|----------|----------------------|
| David, G 2018, Health Benefits of Going On-<br>Country  | Going on<br>Country             | Going on Country investigated the potential health benefits of self-initiated activities and existing community driven pathways that are important for improving health and wellbeing in the remote area of the Groote Eylandt.   | Undetermined        | Cultural<br>Connection    |          | x        |          |                      |
| Davison, B, Nagel, T & Singh, GR 2017, 'Life, lifestyle and location: examining the complexities of psychological distress in young adult Indigenous and non-Indigenous Australians', Journal of Developmental Origins of Health and Disease, vol. 8, no. 5, pp. 541-549.                         | Life Course<br>Program          | The Life Course Program examines the effect of early like factors on later health. There is a particularly focus on assessing the life stressors including not having enough money to buy good or pay bills or their house not having enough space for the people who live there. Concluded there is a need for increased efforts to address inequality and social disadvantage that creates constant stress and increases risk of disease. | Undetermined        | No Primary<br>Determinant | x        |          |          |                      |
| NSW Department of Health 2010, Closing the gap: 10 Years of Housing for Health in NSW An evaluation of a healthy housing intervention.  | Housing for<br>Health           | Housing for Health is a survey and fix approach for improving living conditions. The program aims to assess, repair and or replace essential health hardware so that houses are safe and occupants can carry out health living practices, reducing the risk of disease and injury.  | State<br>Government | Housing                   |          | x        |          |                      |
| Jersky, M, Titmuss, A, Haswell, M, Freeman, N, Osborne, P, Callaghan, L, Winters, J, Fitzpatrick, S & Zwi, K 2016, 'Improving health service access and wellbeing of young Aboriginal parents in an urban setting: mixed methods evaluation of an arts-based program', Australian and New Zealand | Ngala Nanga<br>Mai; We<br>Dream | The Ngala Nanga Mai (We Dream) program is an arts based program for young Aboriginal parents and their children which aims to enhance early health care service access, education and social connectedness to impact on health outcomes. The program provided art sessions, health talks, cultural events, art  | State<br>Government | Education                 |          | x        | x        | x                    |

| Reference   | Program<br>Name   | Program Summary  | Context             | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|---|--|---------------------|---------------------------|----------|----------|----------|----------------------|
| Journal of Public Health, vol. 40, no. S1, pp. S115-S121.   |   | exhibits, childcare, transport, TAFE enrolment and tutoring services and was hosted within the local community health facility. The program was supported by an Aboriginal health education officer, early childhood nurse, social worker and paediatric doctors.  |                     |                           |          |          |          |                      |
| Kildea, S, Hickey, S, Nelson, C, Currie, J, Carson, A, Reynolds, M, Wilson, K, Kruske, S, Passey, M, Roe, Y, West, R, Clifford, A, Kosiak, M, Watego, S & Tracy, S 2017, Birthing on Country (in Our Community): A case study of engaging stakeholders and developing a best practice Indigenous maternity service in an urban setting, | Birthing in our<br>community<br>program                             | Birthing in our community program is a community engaged and informed partnership model of maternity and child health care. The program was delivered through a partnership between a large tertiary hospital and two local ACCHS. The program includes 24/7 midwifery care in pregnancy to six weeks postnatal, supported by Indigenous health workers, and a team coordinator. | State<br>Government | No Primary<br>Determinant | x        |          |          |                      |
| LoGiudice, DC, Smith, K, Shadforth, G,<br>Lindeman, M, Carroll, E, Atkinson, D,<br>Schaper, F, Lautenschlager, N, Murphy, R &<br>Flicker, L 2012, 'Lungurra Ngooraa pilot<br>model of care for aged and disabled in a<br>remote Aboriginal communitycan it work?',<br>Rural & Remote Health, vol. 12, p. 2078.                          | Lungurra<br>Ngoora pilot<br>program                                 | Lungurra Ngoora pilot program is a culturally appropriate pilot model of care and respite for frail, aged and those with physical and mental disabilities. The program provided a range of services including coordination of essential support such as home services, transport, respite, personal care and advocacy.   | State<br>Government | Health<br>System          | x        |          |          |                      |
| Lowell, A, Kildea, S, Liddle, M, Cox, B & Paterson, B 2015, 'Supporting Aboriginal knowledge and practice in health care: lessons from a qualitative evaluation of the strong women, strong babies, strong culture program', BMC Pregnancy & Childbirth, vol. 15, p. 19.  | The strong<br>women,<br>strong babies,<br>strong culture<br>program | The Strong women, strong babies, strong culture program aims to improve health and wellbeing of mothers and their babies, strengthen families through cultural practices and promote early intervention to improve the health of Aboriginal women and their babies.  | State<br>Government | Health<br>System          | x        |          |          |                      |

| Reference   | Program<br>Name                                      | Program Summary   | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|--|---|---|---------------------------|----------|----------|----------|----------------------|
| McCalman, J, Searles, A, Bainbridge, R, Ham, R, Mein, J, Neville, J, Campbell, S & Tsey, K 2015, 'Empowering families by engaging and relating Murri way: a grounded theory study of the implementation of the Cape York Baby Basket program', BMC Pregnancy & Childbirth, vol. 15, p. 119.   | Baby Basket<br>Program                               | The Baby Basket program was developed for the remote Cape York region and aimed to improve the attendance and engagement of Indigenous women at antenatal and postnatal clinics by providing three baskets of maternal and baby goods and associated health education.  | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Health<br>System          | x        |          |          |                      |
| McCarthy, M 2010, 'Telehealth or Teleeducation? Providing intensive, ongoing therapy to remote communities', Studies in Health Technology & Informatics, vol. 161, pp. 104-111.   | RIDBC<br>Teleschool                                  | RIDBC Teleschool utilises videoconferencing technology to provide specialist hearing and vision support to children living in rural and remote areas of Australia, including children in Indigenous communities.  | Non<br>Government<br>Organisation                               | Health<br>System          | x        |          |          |                      |
| Medlin, LG, Chang, AB, Fong, K, Jackson, R, Bishop, P, Dent, A, Hill, DC, Vincent, S & O'Grady, KA 2014, 'Indigenous Respiratory Outreach Care: the first 18 months of a specialist respiratory outreach service to rural and remote Indigenous communities in Queensland, Australia', Australian Health Review, vol. 38, no. 4, pp. 447-453. | Indigenous<br>Respiratory<br>Outreach Care<br>(IROC) | IROC used seven travelling multidisciplinary teams to provide specialist respiratory outreach medical teams in rural and remote Indigenous communities in Queensland.   | State<br>Government   | Health<br>System          | x        |          |          |                      |
| Middleton, P, Bubner, T, Glover, K, Rumbold, A, Weetra, D, Scheil, W & Brown, S 2017, "Partnerships are crucial": an evaluation of the Aboriginal Family Birthing Program in South Australia', Australian & New Zealand Journal of Public Health, vol. 41, no. 1, pp. 21-26.  | Aboriginal<br>Family<br>Birthing<br>Program          | The Aboriginal Family Birthing Program provides culturally competent antenatal, intrapartum and early postnatal care for Aboriginal families in metropolitan, regional and remote/very areas of South Australia. Aboriginal Maternal and Infant Care Workers and midwives work in partnership including health promotion and education, advocacy, access to social health support, clinical care, | State<br>Government   | No Primary<br>Determinant | x        |          |          |                      |

| Reference  | Program<br>Name                                       | Program Summary  | Context             | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|--|---|--|---------------------|---------------------------|----------|----------|----------|----------------------|
|  |   | supporting women in labour and birth and supporting in the first 6-8 weeks after the birth.  |                     |                           |          |          |          |                      |
| Munns, A, Toye, C, Hegney, D, Kickett, M, Marriott, R & Walker, R 2018, 'Aboriginal parent support: A partnership approach', Journal of Clinical Nursing, vol. 27, no. 3-4, pp. e437-e450.   | Aboriginal<br>Parent<br>Support<br>Program            | The Aboriginal parent support program provides culturally relevant community child health practice through home visiting in an urban Western Australian setting. The program includes peer support workers, responding to the impacts of the social determinants of health and interagency collaboration.                                  | Undetermined        | No Primary<br>Determinant |          | х        |          |                      |
| Raven, M, Bates, S, Kayess, R & Fisher, KR 2015, Evaluation of Services Our Way, Social Policy Research Centre (UNSW). <a href="https://apo.org.au/node/53221">https://apo.org.au/node/53221</a> .   | Services Our<br>Way                                   | Services Our Way is a NSW Department of Families and Community Services model designed to build the capacity of Aboriginal people to facilitate greater access to disability services and encourage self-directed support. The program provides access to services and support to participate in social, economic and cultural activities. | State<br>Government | Health<br>System          |          | x        |          |                      |
| Sinclair, C, Stokes, A, Jeffries-Stokes, C & Daly, J 2016, 'Positive community responses to an arts-health program designed to tackle diabetes and kidney disease in remote Aboriginal communities in Australia: a qualitative study', Australian & New Zealand Journal of Public Health, vol. 40, no. 4, pp. 307-312. | Western Desert<br>Kidney Health<br>Project<br>(WDKHP) | The WDKHP is aimed at prevention and early detection to improve the management of kidney disease. The innovative clinical screening, arts-health and community development program is provided by Aboriginal health workers  | Undetermined        | Health<br>System          | x        |          |          |                      |

| Reference   | Program<br>Name   | Program Summary  | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|---|--|---|---------------------------|----------|----------|----------|----------------------|
| Smith, AC, Armfield, NR, Wu, WI, Brown, CA, Mickan, B & Perry, C 2013, 'Changes in paediatric hospital ENT service utilisation following the implementation of a mobile, indigenous health screening service', Journal of Telemedicine & Telecare, vol. 19, no. 7, pp. 397-400. | Mobile ear-<br>screening<br>service                       | The mobile ear-screening service was led by a trained Indigenous health worker who routinely travelled to 21 schools in the South Burnett region in QLD. Records were uploaded to a secure databased and reviewed by the END team and the Royal Children's Hospital who would devise treatment plans remotely with outreach visits twice per year. | State<br>Government   | Health<br>System          | X        |          |          |                      |
| Terare, M, McDonnell, C & Wilson, G 2012,<br>'The chronic care service enhancement<br>program', New South Wales Public Health<br>Bulletin, vol. 23, no. 3-4, pp. 58-59.   | The Chronic<br>Care Service<br>Enhancement<br>Program     | The Chronic Care Service Enhancement program aims to improve coordination and management of care for Aboriginal people with or at risk of chronic disease.   | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Health<br>System          | X        |          |          |                      |
| Tibby, D, Corpus, R & Walters, DL 2010,<br>'Establishment of an innovative specialist<br>cardiac indigenous outreach service in rural<br>and remote Queensland', Heart, Lung &<br>Circulation, vol. 19, no. 5-6, pp. 361-366.   | Innovative Specialist Cardiac Indigenous Outreach Service | The Innovative Specialist Cardiac Indigenous Outreach Service provides outreach services to Indigenous communities in rural and remote locations through community participation, disease self-management, local health care workers, and the translation of scientific knowledge of disease process into community understanding.                 |   | Health<br>System          | x        |          |          |                      |
| Vallesi, S, Wood, L, Dimer, L & Zada, M 2018, "In Their Own Voice"-Incorporating Underlying Social Determinants into Aboriginal Health Promotion Programs', International Journal of Environmental Research & Public Health [Electronic Resource], vol. 15, no. 7, p. 18.       | The Heart<br>Health Program                               | The Heart Health Program is a culturally sensitive cardiac rehabilitation program which provides a holistic approach to chronic disease management. The program has been intentionally designed and structured in recognition of the social determinants of Aboriginal health and wellbeing.   | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | No Primary<br>Determinant |          | x        |          |                      |

| Reference   | Program<br>Name   | Program Summary   | Context   | SDH<br>Addressed          | Implicit | Explicit | Measured | Reported<br>Outcomes |
|---|---|---|---|---------------------------|----------|----------|----------|----------------------|
| Wong, R, Herceg, A, Patterson, C, Freebairn, L, Baker, A, Sharp, P, Pinnington, P & Tongs, J 2011, 'Positive impact of a long-running urban Aboriginal medical service midwifery program', Australian & New Zealand Journal of Obstetrics & Gynaecology, vol. 51, no. 6, pp. 518-522. | The Winnunga<br>Nimmityjah<br>Aboriginal<br>Health Service<br>Midwifery<br>Access Program | The Winnunga Nimmityjah Aboriginal Health Service Midwifery Access Program provides access to antenatal care, birth support and postnatal care to improve pregnancy and birth outcomes for Aboriginal and Torres Strait Islander women.   | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | Health<br>System          | x        |          |          |                      |
| Zarnowiecki, D, Nguyen, H, Catherine, H,<br>Boffa, J & Segal, L 2018, 'The Australian<br>Nurse-Family Partnership Program for<br>Aboriginal mothers and babies: Describing<br>client complexity and implications for<br>program delivery', Midwifery, vol. 65, pp. 72-<br>81.         | The Australian<br>Nurse-Family<br>Partnership<br>Program<br>(ANFPP)                       | The Australian Nurse-Family Partnership Program is a home visiting program for Aboriginal mothers and infants from pregnancy to the second birthday. The program aims to disrupt intergenerational cycles of poor health, social and economic disadvantage to improve outcomes. | Aboriginal<br>Community<br>Controlled<br>Health<br>Organisation | No Primary<br>Determinant |          | x        |          |                      |

# APPENDIX 5.1: CULTURAL PATHWAYS PROGRAM PROTOCOL

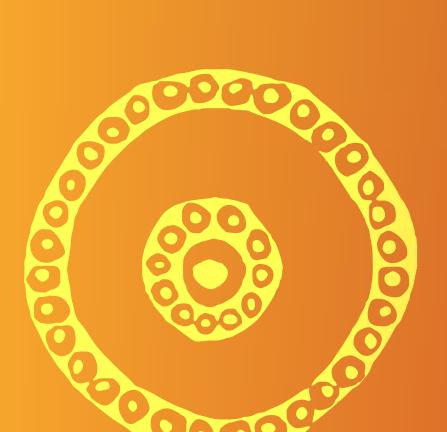


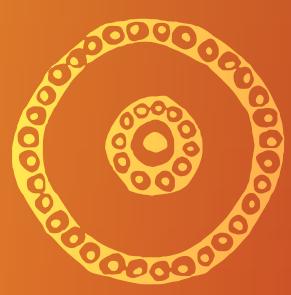






# Cultural Pathways Program Protocol





| This protocol was developed for the Cultural Pathways Program implemented by Wardliparingga Aboriginal Health Equity, SAHMRI and funded by the Wyatt Benevolent Institution.  |
|---|
| The following citation is recommended:  |
| Brodie, Tina. Howard, Natasha. Cantley, Luke. Cooper, Peita. Pearson, Odette and Brown, Alex. 'Cultural Pathways Program: Protocol' <i>Wardliparingga Aboriginal Health Equity,</i> SAHMRI, Adelaide, 2023.               |
| Wardliparingga is a word of the Kaurna people, traditional owners of the Adelaide plains. It means 'house river place' and is also the term for the Milky Way reflected in the River Torrens which runs alongside SAHMRI. |
| Graphic Design by Karko Creations   |

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3

### 1. Purpose, Scope & Related Internal Policies

#### **Purpose**

This document describes the requirements for the management of the Cultural Pathways Program with regards to the processes, guidelines and templates, and includes the engagement of, and continued involvement with, the participants recruited for the program.

#### Scope

This document is applicable to all staff employed for the delivery of the Cultural Pathways Program, this includes Facilitators and other staff involved with the administration of the program.

#### **Related Internal Policies**

- SAHMRI WHS
- SAHMRI WHS Risk Management
- SAHMRI Working Alone, In Isolation or Remotely
- SAHMRI Smoke-Free Work Environment
- SAHMRI Incident Reporting and Investigation

#### **Related External Policies**

- · Health Care Act 2008
- Mental Health Act 2009
- Child Protection Act 1993

### 2. Program Overview, Aims, Objectives & Principles

The Cultural Pathways Program is run by Wardliparingga Aboriginal Health Equity Theme, at the South Australian Health and Medical Research Institute (SAHMRI) and receives funding from the Wyatt Benevolent Institution. The Cultural Pathways Program is a response to community identified needs, designed and led by Aboriginal people and informed by holistic views of health. The Cultural Pathways Program aims to identify the social and cultural needs of Aboriginal people, supporting empowerment of individuals and services to act on the determinants of health.

#### Aim

The Cultural Pathways Program aims to identify the social and cultural needs of Aboriginal people, supporting empowerment of individuals and services to act on the determinants of health.

#### **Objectives**

#### People and community

- Identify social and cultural needs within individuals, families and communities
- Practice strengths-based approaches with participants and their immediate family/ community to assist them in achieving their identified goals.
- Broker relationships between Program participants and service providers.

#### **Services**

- Develop relationships with service providers across sectors and settings
- Gain knowledge on service eligibility requirements and the capacity to facilitate participant connections
- Refer participants into services to meet identified social and cultural needs

#### **System**

- Evaluate people/community and service connections
- Capacity develop Aboriginal students and staff in public health practice
- Leverage further funding to support Pathways system implementation
- Inform conversations to advocate for policy and systems improvements

### 3. Facilitator Description, Support and Safety

Program Facilitators engage with individuals, families and communities across South Australia to offer social assessments, develop rapport and facilitate the development of selfdirected and self-prioritised plans to assist participants in managing the issues that are important to them and that may be inhibiting their ability to manage their own health. Furthermore, Facilitators engage with a range of external stakeholders including government and non-government organisations/services, Aboriginal Community Controlled Health Organisations, and academia. Developing and maintaining relationships with Aboriginal services, communities and other organisations is a core responsibility and assists in brokering relationships for Program participants.

The Program consists of two Facilitators; one male, one female. Having both male and female Facilitators ensures that cultural gender sensitivities are represented throughout the entirety of the program.

#### **Support and Safety**

Facilitators are supported by the Clinical Research Associate to provide consistent services to participants, manage workload, support wellbeing and shared-clinical decision making through a range of structures including:

#### **Case Planning Discussions**

Case Planning Discussions are conducted weekly and are designed to:

- Support planning and strategies for engagement as needed
- Support consistent and shared decision making throughout engagement with participants. For example, when unable to contact, lost contact, non-engagement and closure.
- Provide a reflective mechanism to assist with the scope of the program, given the primary aim of the program is to provide service connections.
- Discuss complex problems for team input.
   For example, mental health, child protection etc.

Agenda items for Case Planning Discussions are specific and relevant to clinical practice (the direct provision of services to participants).

#### One to One Yarning

Weekly/fortnightly opportunities for one to one discussions to support:

- Caseload management including numbers and complexity to support Facilitators.
- Service delivery planning, to share the load and have supported conversations about plans for participants, participants needs' and any support or training Facilitators may need to best support participants.

#### **Debriefing Opportunities**

Facilitators have access to debrief as needed to support working at off-site locations in complex situations where the unexpected can happen. Examples of how debriefing may be utilized include:

- To yarn about a visit "I had this visit and I wanted to yarn about..."
- For advice or direction "I want a second opinion..."
- To Escalate an issue "I am worried about how stressed my client was..."

#### **Pathways Facilitator Reflections**

Facilitators can discuss and identify any challenges, barriers and enablers and general comments or thoughts including but not limited to the following themes. The themes are a guide for the type of reflections Facilitators may like to share to adapt, improve and evaluate the Pathways Program.

#### **Participant**

- Participant response to program
- Response to tools
- Response to strengths based/participant focused approaches
- · What seems to work well or what doesn't
- Reflections of participant change process

#### **Practice**

- Facilitator experience of delivering intervention
- Tools (delivery experience of Facilitator)
- Delivery modes/methods/approaches
- Record keeping/data collection

#### Stakeholder/Services

- Responsiveness
- Cultural appropriateness
- Flexibility
- Referral processes (waitlists, eligibility)

#### Context, System, Policy, Organizational

- Wyatt (KPIs, requirements, expectations)
- Broader social issues impacting the participant/delivery of intervention (racism, housing, cost of electricity, cost of living, and services not available)
- Research/service delivery considerations

#### **Pathways Facilitator Safety Planning**

Consistent with SAHMRI WHS and Working in Isolation Policies, the Cultural Pathways Program is required to ensure the safety and wellbeing of Facilitators as they carry out their duties. The Program is delivered in a range of settings; therefore, for all visits undertaken off site (not at SAHMRI) the following will be adhered to:

#### **Buddy System**

- Outlook calendar bookings which include Participant ID and address details
- Location of sessions
- Yammer update at the beginning and end of the scheduled appointments (see below for Yammer description)
- Facilitators will check in via Yammer or telephone when a scheduled appointment is 30 minutes over the scheduled time, and update with new expected completion time
- If the Facilitator does not check in, a team member will contact to check progress
- If not contactable the buddy will contact the Clinical Research Associate for further action

Yammer is a social networking mobile app used to connect and engage with one another across organizations. The Cultural Pathways Program uses Yammer to keep track of team members when they are not in the office.

#### **Home Visiting**

For home visiting, it is encouraged that first visits be arranged in neutral locations or that Facilitators do not attend unfamiliar homes alone. In circumstances where this is not possible, Facilitators will engage in Safety Planning with the Clinical Research Associate to establish a plan for visiting the home.

For visits that do occur within the home, Facilitator safety is the highest priority. Facilitators will always plan for their safety by taking note of exits, who else is in the home, identifying any hazards and planning for their safety accordingly. Facilitators will safely end the visit and leave at any time if necessary.

#### In an emergency

In the case of an emergency, Facilitators will contact required Emergency Services:

Police, Ambulance, Fire 000

Facilitators have access to SAHMRI Employee Assistance Program 1300 667 700

#### 4. Receiving Referrals

#### Receiving a Referral

Participants of the Aboriginal Diabetes Study (ADS) will be referred into the Cultural Pathways Program by an ADS Field team member (e.g. male or female Aboriginal Health Worker, Allied Health Professionals). Participants can also be referred into the Program via a process of self-referral, or as a group or community.

### Referral from the Aboriginal Diabetes Study

Referrals from the ADS into the Cultural Pathways Program, can be received by:

- A completed Cultural Pathways Program Referral Form for an individual participant OR:
- A completed bulk referral spreadsheet template for a larger number of participants
  - Referral form for each participant must be included when emailing spreadsheet through

Using the Program's referral form, the ADS Field team member will complete all details requested.

The participant information required in the referral template is as follows:

- Name of the ADS Field Team member who made the referral
- · Self-idenitfied Gender of the participant
- Gender of the Facilitator they prefer to engage with, if any preference
- Participant first and last name
- Participant date of birth
- Participant ADS ID
- Participant's residential address
- Participant's phone and/or mobile number (if via a secondary contact, name of that person)
- Best contact method for the participant
- Any information associated with the referral reason (if any)

The completed referral form will be forwarded to the pathwaysprogram@sahmri. com mailbox and distributed as indicated in the referral template. If the ADS Field team member does not have all relevant information, they should indicate this on the form with 'N/A' (not available).

#### Self-Referral

A self-referral is a referral who has received information about the Cultural Pathways Program from a source other than the ADS or Nunkuwarrin Yunti. If the self-referee makes direct contact with a Facilitator, the Facilitator needs to provide them with information about the program and offer to send them a copy of the Program flyer either via mail or email. If they consent to participating, they can then progress through the referral process.

#### **Family Referral**

A Family referral is a potential participant who is a family member of a current participant. They can contact a Facilitator directly, and the Facilitator will follow the same process as for 'self-referral'.

#### **Community Referral**

A Community referral is a different type of referral and presents a potential for Facilitators to conduct group sessions or engage third parties to conduct sessions. For example, where a community identifies a specific need (housing, budgeting), they can be invited to participate as a group. If the expertise lies outside of the scope of the Facilitator, the Facilitator can engage a service provider to present to the group. For sourcing a service provider refer to the Stakeholder Engagement section.

#### **Internal Referral**

An Internal referral is an employee, student or intern that works in Aboriginal Health Equity. Due to conflict of interest, Facilitators are not to take on internal referrals as participants. Facilitators have a duty of care and are required to discuss alternative options with the referral (e.g. employee assistance program for counselling or Wirltu Yarlu (University of Adelaide) or Wirringka (UniSA) for students). Facilitators can still complete referrals into external services/ programs and are to provide support to the referral while they're accessing the service/ program.

#### **Referral Processing**

Once referrals are received, they are assigned to the appropriate Facilitator to review them for any missing information. If the referral is received via email, the Facilitator is to print off the referral form. The Facilitator is to create a hard copy file for each referral, labelled with their REDCap ID number containing the referral form and that file is to be stored in the lockable filing cabinet in the data room in Aboriginal Health Equity, level 4.

It is essential for the referral to contain information required by the Program so prompt contact can be made with the participant. When a referral is received, the registration process will have specific timeframes:

- within 24 hours check all participant details and allocate to a Facilitator to create a case record
- within 48 hours make the initial phone contact with a participant
- within 48 hours respond to the referrer to advise receipt of referral

If a referral is received with missing information, the Facilitator will contact the referrer to obtain further information or confirm there are no other details available. Where the Facilitator needs to contact the referrer, they are to ensure strict adherence to confidentiality requirements, ensuring no further information is exchanged without consent. If there is missing information relating to some of the fields in the referral template, and the referring staff member has noted 'N/A' (not applicable/available), then the information can be assumed complete.

Facilitators will declare any conflict of interest and a plan will be established before proceeding:

- If a referral is received by the Facilitator, and they recognize an existing relationship or connection with the referee, then the Facilitator is required to raise the issue with the team.
- Once having discussed the concern with the team, and the team agrees there is a conflict, then the referral is forwarded to the next appropriate Facilitator.
- If the team agrees there is no existing conflict, the referral can be progressed by the Facilitator in the usual manner.
- If the team agrees there is no conflict, but the participant raises their concern, then the team can agree there is just cause to refer on to another Facilitator.
- If the team agrees there is no conflict, the Facilitator commences engaging with the participant and then raises concern, the team can agree for the participant to be referred to another Facilitator.

Once the Facilitator has completed the registration of the participant, they are now able to continue the process by initiating contact with them.

#### 5. Initial Contact with Participant

The initial contact by the Facilitator to the participant will occur within 48hrs of receiving the referral. The Facilitator, following the Script (see Participant Engagement Script), will use the initial contact to introduce the program.

The Facilitator will confirm the referral and schedule the first session. The first session should be at a time and location convenient for the participant and can be conducted in a range of settings including; the participants' home, at a local location (health service, park or café), or at SAHMRI. The Facilitator will ensure the participant understands engagement in sessions is completely voluntary and that they are comfortable with the process.

For details relating to the first session and the engagement process refer to 'Participant Engagement'.

#### If contact un-successful

If there is no response on the phone number provided, the Facilitator will leave a voice mail, where possible, or send a text message as per the Voicemail – Text Attempt 1 Script (see Participant Engagement Script). The Facilitator is to ensure the guidelines and script are adhered to for consistency and participant confidentiality.

When participants are not able to be contacted via the first call, a second attempt to contact must be made within 48hrs after the first attempt. If required, the third attempt will be made at a different time and day to previous attempts in case participants have other obligations that restrict contact at certain times. No less than three attempts will be made to contact a participant within 14 days from receiving the referral. Outlook reminders in the Facilitators calendar can be used to ensure follow up is completed in a timely manner.

If after three attempts the Facilitator is still unable to contact, a no contact letter will be sent to the participant's listed address. The Facilitator is to wait one week before attempting a final phone call to the participant.

If the participant does not answer the final call, the Facilitator is to leave a voicemail or send a text message advising that the participant can contact Facilitator at any time to hear more about the program. See no contact flowchart.

#### 6. Participant Engagement

A key element of the Cultural Pathways Program is working in partnership with participants. The Facilitator is responsible for developing a relationship and rapport from the first engagement. There are a range of skills and strategies that can support this including, but not limited to:

- Some key Aboriginal health and strengthsbased skills and competencies
- Empathy, getting a sense of where another person is coming from or what they are experiencing
- Showing respect by actively listening to what the participant is saying (maintaining eye contact, using appropriate body language) and responding appropriately (paraphrasing back to the participant)

#### **Preparation**

There are a range of important administrative requirements that support working with participants:

- Call the participant to arrange session
- Arrange location and time to meet, book location if needed (at least a week in advance)
- Book car (book when session is confirmed)
- Place session details in own calendar (Participant ID number, time and location of session)

#### **First Session**

The first session will be scheduled to occur as soon as possible within 14 days of the initial contact with the participant.

The Facilitator will take time to prepare for the first session, considering:

- · Whether the session is with an individual. group or community
- The location of the session (where does the participant want to meet)
- What the Facilitator will need to take with them to the session
- How the Facilitator will approach achieving the key outcomes of the first session whilst also being flexible and developing a relationship

To guide preparation for the first session the Facilitator will follow what is outlined below

- Arrive 10mins prior to appointment
- The Facilitator will focus on building rapport, making the participant feel as comfortable as possible
- Introduction of the program and obtain consent to participate as per Introduction of CPP to participant script (see Participant Engagement Script).
- Completion of the First Screening Tool as per First Screening Tool Guidelines & Script
- Talk about the research project, what it is, what is involved

#### What to Bring

- Data Collection Form (2 copies of consent form, one for participant to keep)
- Pens, paper
- Mobile phone & charger
- Emergency numbers in mobile phones
- Once the Facilitator has met with the participant, they are to:
- · Complete data entry on REDCap (see Documentation & Data Entry Protocol)
- Secure the Data Collection Form and any other hard copy documents the participant folder
- If needed, have a discussion with Clinical

Research Associate to reflect on meeting and plan next steps

Throughout the provision of the Cultural Pathways Program service there are a range of key objectives to be achieved:

- Assessment
- Priorities and Goal Setting
- Advocacy and Service Connection

#### **Data Collection Form**

Facilitators utilise a data collection form (DCF) as a hard copy way to collect four different sets of information from the participant participant identifiable data (name, address, language group, etc), participant consent for inclusion in the program evaluation, first screening tool and goal setting. The data collection form is kept in the participants file in the lockable cabinet in the data room.

#### **Screening Tool**

Facilitators utilise a culturally adapted screening tool to identify any unmet health and social needs. The screening tool outlines 13 domains related to the social determinants of health. The screening tool assists the Facilitator in understanding the participants needs and helps the participant in prioritizing these needs in order to set goals. The screening tool is generally completed within the first face-to-face session.

#### **Priorities and Goals**

Identifying priorities and setting goals follows the screening tool, which facilitates the identification of participant health and social needs and provides the basis to prioritize these needs and set goals.

Facilitator will note the needs identified through the first screening tool and revisit these with the participant to identify goals, along with steps and actions to achieve those goals. Steps are detailed in the Priority and Goal Framework and Guidelines.

#### **Advocacy and Service Connection**

A key part of the service provided is to link participants with services that can support them in achieving their identified goals. The provision of support will be tailored to meet each participants' need. For some participants, the support will be quite intensive, modelling how to link with services and actively supporting access to services. However, other participants may need less intensity and may be able to access services themselves with support from the Facilitator. The Facilitator will always be working towards the participant being able to do this independently.

The Facilitator will utilise mobile phone and laptop to provide on the spot, and proactive support where possible to support increasing to participants understanding of where and how they can obtain the information they need.

To provide advocacy for participants already connected with a service, the Facilitator will obtain permission to contact that service on behalf of the participant by using the Advocacy Consent Form.

#### **Participant Safety and Risk**

If a participant is highly distressed, becomes highly distressed or experiences a crisis event, the Facilitator is to refer to the Distressed Participant protocol.

Mandatory reporting describes the legal obligation of certain professionals and community members in South Australia to report incidences of child sexual abuse, physical abuse, emotional abuse and neglect. As mandated reporters, Facilitators will notify the Department for Child Protection if there are reasonable grounds to suspect that a child has been or is being abused or neglected.

Participants engaging with the program are likely to experience multiple challenges including mental health, homelessness and domestic and family violence. Where there is an immediate risk to safety, Facilitators will contact the appropriate emergency services if required. If there is no immediate threat Facilitators will with the Participant either contact crisis services or provide the details for the participant to contact the service required.

#### Non-Engagement/Lost Contact

There could be a range of reasons why participants do not engage with the program or may no longer be contactable. A Facilitator should always be flexible with their approach, and:

- Discuss with the participant their continued engagement, the voluntary nature of the program and their right to withdraw at any time
- Discuss if there is anything that would further support their engagement

If the Facilitator is unable to contact the participant after an extended period of time, they should make at least three attempts before presenting at a Case Planning Discussion. From this discussion, the team can decide whether to:

- Contact a secondary contact
- Contact any supports or service providers
- Send Lost Contact Letter
- Attempt to contact again within timeframe agreed through care planning process

If successful in making further contact, and the participant is still interested in engaging, resume sessions. If the number has been disconnected and there is no third party/next of kin noted, then a decision needs to be made about forwarding correspondence to the participant's address.

If the attempts to contact the participant are unsuccessful, or the participant advises they do not wish to continue, the Facilitator should then undertake a case closure process, outlined below in Participant Case Closure.

#### 7. Stakeholder Engagement

The successful engagement of key stakeholders is pivotal in terms of supporting participants to experience forward momentum in achieving their goals. The relationship the Facilitator, and Wardliparingga, nurtures with stakeholders is critical in terms of enabling participants to achieve this success. These stakeholders can take on the form of individuals, or as complete entities, and may include, but not limited to, various health and social services, education and training services, recreation and social activity providers, and income/employment services.

| Things to consider                         |   |
|--|---|
| Where are you going?                       | → Establish what community you are going to visit and commence contacting the service providers from that area. Prior to contacting services, considering if it is appropriate to contact Aboriginal services to confirm whether or not there are any 'sorry business' arrangements happening locally. If these services are uncertain, confirm with management as to the appropriate contacts within each of the communities  → Using the Service Engagement Script, initiate contact with the service providers in the area and arrange to meet with them.  → Visiting services in the prescribed area can also be useful in terms of sharing information, meeting staff and confirming referral processes. |
| How long are you going for?                | <ul> <li>→ The length of the visit will determine some of the items needed:</li> <li>Participant DCF's and program information</li> <li>Vehicle</li> <li>Accommodation</li> <li>Flights</li> <li>Laptop &amp; charger</li> <li>Work mobile</li> </ul>   |
| Who are you going to meet with?            | → The type of services engaged will be influenced by the needs of the participants in the area  |
| How will you deliver the Pathways service? | → From the participant's home, or a café, or other premises   |
| What's in the area?                        | <ul> <li>→ Compile a list of who the service providers are</li> <li>→ Arrange to visit them if possible</li> <li>→ Take CPP information packs</li> </ul>  |

#### Contacting the service provider:

From the initial contact, making a good first impression is essential to establishing and continuing an effective working relationship with a service provider. The relationship created with the service provider will be the basis of how it is continued.

Undertaking the approach with each service provider will have its similarities, and its uniqueness. Some things to think about:

- · Need to consider the purpose of the contact.
- The type and amount of communication required, and
- The investment of the relationship building process.

Initial contact with a service provider in a variety of ways:

Visiting services (metro)

- Calling services (metro/country)
- Emailing introductory letter with flyer attached (metro/country)

#### Referring participants to service providers:

Where possible, participants should identify and access services for themselves. If this is not possible, the Facilitator will act as advocate on the participant's behalf. Advocacy will, ideally, be a temporary measure until participants are able to access services independently.

Coordination of services by the Facilitator should first be attempted by phone and email communication. Where there is a longstanding relationship between services and the Facilitator, this communication may take place in person rather than through a formal letter or email.

All communication with the service provider will need to be recorded in the correct participants episode on REDCap.

# It is important that all services are informed of:

- Name and contact details of the Facilitator
- Name, address and date of birth of the participant
- Reason for the referral
- Existence of any other agency support in place (if known)
- Facilitator's role within the support plan
- Who to contact should any issues arise

When initiating contact with the service provider, the referral should be sent to the key worker or other named contact person identified within the service. If a participant has not accessed the service before, the Facilitator should phone the service to ascertain the relevant contact person's details before any correspondence is forwarded.

In instances where an email is the first introduction to the service provider contact person, this should be accompanied by the advocacy form, which is to be signed by the participant before any contact with a service provider is had.

In all cases, and as part of the support plan process, the participant should be aware of the role that each service provider plays in the support plan. They should also be aware that each service provider will be individually contacted by the Facilitator.

#### 'Handing over' participants

The 'handing over' of participants comes at a time when the participant agrees they are ready to continue working with the service provider without the support of the Facilitator. At this point, the Facilitator may continue to monitor progress and occasionally contact the participant and the service provider; with the participants consent. The benefits of this are twofold, as supporting the participant and the provider will be crucial to maintaining ongoing working relationships, particularly with services.

#### 8. Participant Case Closure

The duration of active engagement in the program depends on needs and progress towards achieving goals and priorities. In some instances, participants may require short term intensive support and other participants may need longer term support.

Progress towards achieving goals and the potential end of service provision when goals are met is a regular discussion between the participant and the Facilitator as part of regular reviews of progress so that participants are prepared. A closure discussion with the participant occurs when they are ready, and they feel comfortable with moving forwards with their goals on their own (see goals met or goals partially met flowchart).

#### The case closure process:

- · Case Planning Discussion
- Conversation either via phone call or face to face with the participant to confirm case closure
- Participant are be advised they are welcome to make contact in the future
- When engaged with another service:
- Notify relevant service provider/third party if required of case closure

#### **Administrative Tasks:**

- Documentation up to date
- Close episode on REDCap
- Move participants hard copy folder to the closed cases filing cabinet

#### 9. Repeat Episodes

If a Participant makes follow up contact with the Program after case closure, Program could create a follow up Facilitators episode. This can be done by carrying out the following steps:

- Access the program's database (REDCap)
- Select Add/ Edit record
- Using the Search query field, enter the Participants last name
- Search query will display Participant's last name and previous program ID number
- Create new episode by selecting Add/ Edit record
- Using the Participants previous program ID number, create the new episode and allocate the new episode number. For example, CPP0001 would be titled CPP0001 2.

If participant has been closed for more than 6 months, Facilitator is to complete another First Screening Tool with the participant. This will help in identifying any changes in the participants social and cultural needs, compared with the first time the participant entered the program.

#### 10. COVID-19 Follow Up Process

During the outbreak of COVID-19, Facilitators contact all previous program participants to check on their welfare and assist participants in knowing what support is available during this period. This ensures the program continues to uphold its duty of care towards program participants and provides them with an opportunity to re-engage with the program.

Program Facilitators review the program's database and identify previous participants with an episode that is currently closed (Facilitators will commence at the most recently closed participant, working backwards to the first closed participant . Participants are contacted by phone call, text message and/or email, using the scripts (see follow up script).

Participants who initially declined or withdrew will be reviewed last, with a plan to review SOAP notes before making contact. Any

participants that strongly declined will not be contacted, however all others will.

#### **How to Contact:**

- Participants that Facilitators have been in contact with in the last 5 months receive one phone call and then a text (see follow up script) if they do not answer that phone call. No further contact is to be made after the text message and if the participant does not respond within 3 days. Facilitators are to close the episode.
- Participants that Facilitators have worked with longer than 5 months ago receive a text (see follow up script), and a phone call. If the participant does not answer the first phone call, Facilitators will call once more 2 days later at a different time. No further contact is to be made after the sec-ond phone call and if the participant does not answer or return the call within 3 days. Facilitators are to close the episode.
- For participants that originally declined, Facilitators make one phone call and if not answered, follow up with a text message. No further contact is to be made after the text message and if the participant does not respond within 3 days, Facilitators are to close the episode.

If a participant identifies further areas of need, they are to resume active involvement in the program. If a participant declines assistance, the Facilitator is to thank them for their time and not contact them again.

#### **Documenting Engagement:**

Facilitators are to document all contact/s with participants in REDCap by creating a second (or third) episode for each participant and record all contact in the SOAP notes. Furthermore, Facilitators have an excel spreadsheet with all closed participants IDs and date of closures. Facilitators are to document the date of contact and what the outcome is.

# 1. Cultural Pathways Program Referral Form

| Date                        |  |
|-----------------------------|--|
| Referring ADS Staff Member: |  |
| ADS #:                      |  |

Please accept this referral into the Cultural Pathways Program.

This participant has been assessed by the Aboriginal Diabetes Program and has consented to being contacted by a Program Facilitator. They have been advised that their involvement in the program is completely voluntary.

Participant details (please complete all fields)

| Last Name:   |  |  |
|--|--|--|
| First Name:  |  |  |
| Address:   |  |  |
| Contact number:  |  |  |
| Email:   |  |  |
| Preferred method of contact, including best days and time: |  |  |
| Preferred gender of Facilitator (if any):                  |  |  |
| Referral Reason (if any):                                  |  |  |

# 2. Cultural Pathways Program Data **Collection Form**

| PARTICIPANT IDENTIFICATION    |     |     |     |  |  |
|-------------------------------|-----|-----|-----|--|--|
| Program Identification Number | CPP |     |     |  |  |
| Episode Number                | 1st | 2nd | 3rd |  |  |
| Program Facilitator           |     |     |     |  |  |

|                                  | RECRUIT     | MENT          |                       |
|----------------------------------|-------------|---------------|-----------------------|
| Date of referral                 |             |               |                       |
| Referral Source                  | ADS         | Self-referral | Community/Family      |
| ADS identification number        |             |               |                       |
| ADS Team Member Name             |             |               |                       |
|                                  | PARTICIPANT | T DETAILS     |                       |
| First Name                       |             |               |                       |
| Last Name                        |             |               |                       |
| Date of Birth                    |             |               |                       |
| Gender                           | Male        | Female (      | Chose not to identify |
| Recruitment Address              |             |               |                       |
| Community/Town                   |             |               |                       |
| Postcode                         |             |               |                       |
| Recently changed address         | Yes         | No            |                       |
| Language Group                   |             |               |                       |
| Best Contact Number              |             |               |                       |
| Best time to call                |             |               |                       |
| Email                            |             |               |                       |
| Secondary contact (First Name)   |             |               |                       |
| Secondary contact (Last Name)    |             |               |                       |
| Secondary contact (phone number) |             |               |                       |
| Comments:                        |             |               |                       |

# 3. Program Information and Consent Form





## Building stronger, healthier communities through increasing access to health and social services

The Pathways Program works with Aboriginal and Torres Strait Islander people and communities to identify their individual or collective social and emotional wellbeing needs (e.g. transport, housing, healthcare), set goals and make plans to connect to critical services available within the community.

We welcome you to meet with a member of the team face to face or talk over the phone as many times as you need. The program can assist you in working towards your goals by linking you to available services.

Participation in the program is completely voluntary. The program is interested in building a story about how people access services in the community. Based on this information, the program will then report back to the community to discuss what is and isn't working well.

#### **Eligibility**

- Aboriginal and/or Torres Strait Islander
- Age 15 and over
- Living in South Australia

For more information please contact the team on 0436 680 071 or pathwaysprogram@sahmri.com

The Cultural Pathways Program is run by Wardliparingga Aboriginal Research Unit, at the South Australian Health and Medical Research Institute (SAHMRI) and receives funding from the Wyatt Benevolent Institution.





The Cultural Pathways Program is run by Wardliparingga Aboriginal Research Unit, at the South Australian Health and Medical Research Institute (SAHMRI) and receives funding from the Wyatt Benevolent Institution. Wardliparingga have developed a project that seeks to understand what factors are impacting on peoples' social and emotional wellbeing, and then directly connect them with available services. The aim of the Cultural Pathways program is to alleviate stress and worry by increasing your access to support services, and allowing you to benefit from improved health and wellbeing.

The Cultural Pathways Program was created after discussions with many participants and community organisations about the underlying causes of diabetes and its complications. People we spoke to made it very clear that there are many social and community factors which impact on their health. Unfortunately, there are few, if any, programs that work directly with people to support them to improve their health and wellbeing.

This highlighted a lack of programs that work alongside people to assist in reducing stress and worry. The Pathways Facilitators would like to collect and report findings back to your community about its available services, so access can be increased and areas for improvement highlighted. It is your right to participate in research that impacts you and your community, and you may benefit from connecting to services that offer support for health or social needs that are causing you stress and worry. You can even talk with Pathways Facilitators about your community without being involved in the information gathering process. Currently Wardliparingga has been capturing information from different projects including the Aboriginal Diabetes Study.

How often you meet with Pathways Facilitators is your choice, and you also have the freedom to leave the program at any time. Participating in the Cultural Pathways program requires working with a facilitator to ...

- Identify social support needs.
- Create personal goals.
- Contact relevant helpful services.
- Discuss the services contacted.
- Assess the help offered by the services.

Pathways Facilitators are also responsible for ...

- Keeping notes on your support needs, goals and experiences with contacted services.<sup>1</sup>
- Discussing your support needs with you.<sup>2</sup>
- Providing assistance options.3
- Gathering information about your experiences with services in your community.
- <sup>1</sup> Unless permission is given these notes will not be passed onto any other project or service. Paper copies will be destroyed and digitised where possible.
- <sup>2</sup> Please note that the program is not a support or case management service.
- <sup>3</sup> Please note it is your responsibility to choose the appropriate option and independently work towards achieving your goals.

Contact the Pathways Facilitators on 0436 680 071 for more information.

If you have feedback about the program please contact: Prof. Alex Brown, Principal Researcher on 8128 4274, or The Executive Officer AHCSA on 8273 7200.

| Co         | nsent form   |            |   |
|------------|--|------------|---|
| l,         | agree to take part in the Cu   | ıltural    | Pathways program and have read the information above.  (Ethics Approval Number (AHREC): 04-17-733)                            |
| $\bigcirc$ | The project has been explained to me and I have been given the option of having a family member or friend present during this explanation. | $\bigcirc$ | I understand that the program will not publish or pass<br>my information to other projects or services without<br>my consent. |
| $\bigcirc$ | I understand that if my information is published my personal results will remain confidential and unidentified.                            | $\bigcirc$ | I freely give my consent to participate in the project and I have the freedom to withdraw at any stage.                       |
| $\bigcirc$ | I understand the purpose of my involvement in the project.   | $\bigcirc$ | I will make a copy and keep this form when completed.   |
|            |  | Signa      | ature Date  |
| Res        | searcher to complete   |            |   |
| l,         | have described the nature  | of the     | research project to  (Print participants name)  |

Position \_

# 4. Scripts for Participant Engagement

#### **Pre-Phone Call Text**

Hi my name is [name] and I am from the Cultural Pathways Program. I am following up from the Aboriginal Diabetes Study. I'd like to give you a call today between (time frame) to tell you more about the program. Thanks.

#### **Appointment con irmation**

A phone call is made to participants within 48 hours of the Pathways Program receiving the referral from ADS.

Phone calls are to be made at an appropriate time (there is an option in the referral form to indicate best time/day to call).

#### **First Phone Call**

#### Phone call to Participant after referral received from ADS:

Hi, my name is [name] I am a Facilitator with the Cultural Pathways Program. Do you remember the Aboriginal Diabetes Study? They asked you some questions about your health and checked things like your eyes and your feet. We received a referral from (ADS team member name) from the study, do you remember anyone talking to you about the pathways program? The pathways program can chat about what is going on for you and support you to get what you need. Are you happy to organise a time to meet with you and talk more about the program?

- Participant wanting more information
  - o We talk to you about what is going on for you and your community and support you to make plans to identify and access available supports in your community
- Participant saying yes:
  - o Lovely, where would you like to meet? I can come to you, or we can meet somewhere? If you would like to have another person come with you for the first session, that is completely fine.
- Participant saying no:
  - o No worries, up to you but I'm happy to tell you a little more about what our program is and provide any further information.

- o I am happy to send some information to you in the mail if you would prefer this prior to making any commitments.
- o Thank you for taking the time to speak with me. If you would like to chat further about this study. I am happy to post out some information...

#### If there is:

- No answer Facilitator should try again the next day at a different time.
- Voicemail option a message should be left [see example voicemail message attempt 1].

#### Voicemail - Attempt 1

Hello, it's [name] from the Cultural Pathways Program. I'm calling to discuss the program with you and to make a time to catch up if you are interested. Please call or text me back when you are available.

#### **Before First Meeting**

If a first meeting has been arranged, the Facilitator is to send a reminder text either the day before the scheduled meeting, or the morning of the scheduled meeting if the meeting is in the afternoon.

#### **Appointment Reminder message**

Hi [participant name], this is [name] from the Cultural Pathways Program. Just sending a reminder that we are meeting tomorrow at [appointment time], [appointment place]. Please let me know if you need to reschedule.

#### Missed appointment message (Text or Voicemail)

Hi [participant name], this is [Name] from the Cultural Pathways Program. Sorry we didn't catch up for your appointment, would you like to reschedule? Please call or text me back when you are available.

(propose a process for this – a time period in which we need to recall or re text)

# a. Introduction of CPP to the participant

## 1st session (Face to Face)

\*If a third party is present for the first session, ensure they don't provide answers for the participant

Build rapport (how has your day been today, etc)

Thanks for taking the time to meet with me today. I would like to start by sharing with you a little more about who I am and what our program is.

There are many things in life that could impact on your health and wellbeing, these could be things in your community like housing, transport and health services and how you might access them. My role as a Facilitator in the Cultural Pathways Program is for us to work together to identify your needs and connect you with services in your community. During this first session we will discuss what is going on for you which will involve me asking you some questions, what is influencing your health, what services are available, and how we can best support you with what matters most to you. Afterwards, we discuss what your priorities are and what goals you would like to make to assist with what is going on for you. My job after today is to find any available services or programs that I can connect you with to help you achieve those goals.

Do you have any questions before we begin?

#### **Evaluation Consent**

The Pathways team will report back to your community on the findings we discover through these conversations. You can choose if you would like parts of your story to be included in the information shared back to the community. If you choose to share parts of your story, your personal details will remain confidential. We never share information that could identify you. We are interested in sharing information relating to contacting support services, issues where services were not available, or the number of times we meet with participants. If you don't want parts of your story shared in the information we will report back on, that's fine. We will still meet with you as many times as you need and none of this information will be shared.

# Ask the Participant if they would like to be involved in the evaluation process:

**Yes:** complete evaluation consent form

**No:** ask if they have questions relating to any of the information provided, clarify key points - your personal details will not be provided, we are interested in things like how many times we met, what services we contacted, maybe even things like programs or services that are not currently available in your community. The evaluation process gives community members an opportunity to have a voice about supporting their health and wellbeing.

If the answer is still no, inform the participant that we will still meet as many times as they need, and emphasise that their information will not be shared. Do not include Participant in evaluation process.

If the participant is happy to be involved and proceed, they can sign the consent form.

# b. Script for Follow Up Participant **Engagement**

#### If Participant has been involved in the Program:

Hi there. This is [name] from the Cultural Pathways Program. It has been around 3 months since we spoke last, and I wanted to give you a call today to follow up on how things have been going for you.

Since we last talked, have you:

- Continued to get the support you need OR;
- Been able to maintain connections with services we talked about?
- · Are there new challenges you need support with?

#### If the participant states things are going well:

Great, thanks for chatting with me. If things change this is my number here, you're welcome to contact me at any time if you need us

If the participant states things have not been going well:

Can you tell me more about what has been happening for you?

Would you be interested in meeting up again to have a chat about what's going on?

If Participant has not been involved in the Program, but makes contact after receiving the ADS follow up letter:

Hi there. My name is [name] from the Cultural Pathways Program. Thank you for getting in contact with me. What has promoted your phone call today?

\*Participant explains what made them call

Sounds like you have a bit going on. Would you like to make a time to meet up and varn about this further?

## c. Script for Service Providers

#### **Cold Calling:**

Hi, my name is [name] and I am from the Cultural Pathways Program which is a program based in Wardliparingga Aboriginal Health Equity at the South Australian Health and Medical Research Institute. I am calling today to see if you would be interested in making a time to meet and discuss both the Cultural Pathways Program and your service/ program in further detail. I am interested in hearing about what your service/program offers and how I can refer any future participants to you.

#### In person when handing out flyers:

Hi, my name is [name] and I am from the Cultural Pathways Program which is a program based in Wardliparingga Aboriginal Health Equity at the South Australian Health and Medical Research Institute. The Cultural Pathways Program predominantly focuses on addressing the social determinants of health in Aboriginal and Torres Strait Islander people. Do you have an Aboriginal staff member or a Social and Emotional Wellbeing Program that I can get in touch with to discuss the Cultural Pathways Program with further?

If the person says yes: Wonderful, can I have their email address/phone number/contact details?

If the person says no: Not a problem, can I have the contact details for the program

coordinator/service manager?

#### **Emailing:**

Good afternoon/morning,

My name is [name] and I work in the Cultural Pathways Program which is a program that operates out of Wardliparingga Aboriginal Health Equity Theme at the South Australian Health and Medical Research Institute (SAHMRI). I am emailing you today to inform you of the Cultural Pathways Program. We are a program that focuses on addressing the social determinants of health in Aboriginal and Torres Strait Islander people.

Does your service have a Social and Emotional Wellbeing Program and/or an Aboriginal staff member that I can contact to further discuss the Cultural Pathways Program with, as well as referral pathways into your service?

I have attached the Cultural Pathways Program's flyer for more information. If you have any questions, please don't hesitate to contact me on [number] or via email.

Kind regards,

[name]

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# 5. Delivering First Screening Tool

## (Lead discussion into first screening tool)

The first screening tool is a culturally adapted assessment tool that outlines 14 yes or no questions (13 different domains) to assist the Facilitator in identifying any unmet social and cultural needs. The first screening tool assists the Participant and Facilitator in the goal setting process and is generally completed in the first face to face meeting.

#### **Script**

When we spoke about the program earlier, I mentioned that we would ask some questions about what's going on for you. We will work through a questionnaire to get an idea of some of the areas you would like assistance with, and whether this program is suitable for your needs. You can answer yes or no, or if you feel uncomfortable answering a question, just say you would rather not answer and we will move onto the next question. These questions help with me (the Facilitator) understanding of what is going on for you, what supports you might need and how these issues could be addressed.

After completing the screening tool:

Thanks for working through this with me, we have asked you some challenging questions today and just want to make sure you're feeling ok?

| FIRST SCREENING TOOL                     |  |  |
|--|--|--|
| Cultural Pathways Program Participant ID |  |  |
| First Name                               |  |  |
| Last Name                                |  |  |
| DOB                                      |  |  |

|  | i e |    |             |
|--|-----|----|-------------|
| In the last 12 months, have you ever worried about feeding yourself or your family?  | Yes | No | No Response |
| In the last 12 months, have you received a bill and been worried about how you are going to pay it?                                      | Yes | No | No Response |
| In the last 12 months, have you needed to see a doctor or health professional, but couldn't?   | Yes | No | No Response |
| In the last 12 months, have you been unable to make an appointment or get to where you need to go because you didn't have any transport? | Yes | No | No Response |
| Do you have stable and adequate housing at the moment?   | Yes | No | No Response |
| In the last 12 months, have you been worried about work or study?  | Yes | No | No Response |
| Do you ever need help reading or understanding documents or forms (e.g. Centrelink, Medical forms, School forms)                         | Yes | No | No Response |
| Is there something about your health that is worrying you and that you have not got help for?  | Yes | No | No Response |
| Have you been feeling unhappy or no good in yourself or spirit?  | Yes | No | No Response |
| Do you have any big family issues or concerns?   | Yes | No | No Response |
| Do you feel connected to the community in which you live?  | Yes | No | No Response |
| Do you feel safe in your community, family or where you currently live?  | Yes | No | No Response |
| Do you have any behaviours that you know are not good for you that you would like to change or talk about?                               | Yes | No | No Response |
| Do you feel you need more opportunity to learn and share your Aboriginal culture?  | Yes | No | No Response |
| Do you have any other concerns or needs that we have not covered yet?  | Yes | No | No Response |
| Other concerns   |     |    |             |

## 6. Priorities and Goals

Prioritising and setting goals follow the completion of the First Screening Tool. The Facilitator will note the needs identified through the screening tool and revisit these with the participant to identify goals, and steps and actions to achieve those goals. Steps are detailed below.

#### **Step 1: Strengths and Resources**

This provides the opportunity to discuss things which help to keep the participant strong. Discussion can explore family, support networks, people around them, things that are important to health and wellbeing, and any worries that may need to be considered.

#### Step 2: Priorities, Goals and Steps

The participant identifies their highest priority and goals are recorded in order of priority. The role of the Facilitator is to support participants to identify goals that can support a change for them. Facilitators will utilise SMART goal setting framework utilising strengths previously identified to underpin any goals and steps.

# Goal Setting -Measurable -Realistic Time-Based

#### **Step 3: Reviews of Progress**

Important part of goal setting is regular review. This occurs through highlighting and celebrating milestones as they are achieved and adjusting/reviewing goals as necessary. Pre-determined review dates will be set with each goal, these are flexible and agreed with participants. These review dates support:

- Checking progress and to re-prioritise as required;
- Setting future visit frequency / intensity of service provided matches needs and goals;
- Commence exit planning where appropriate.

Documentation and data entry requirements are outlined in the data entry protocol.

#### What keeps me strong



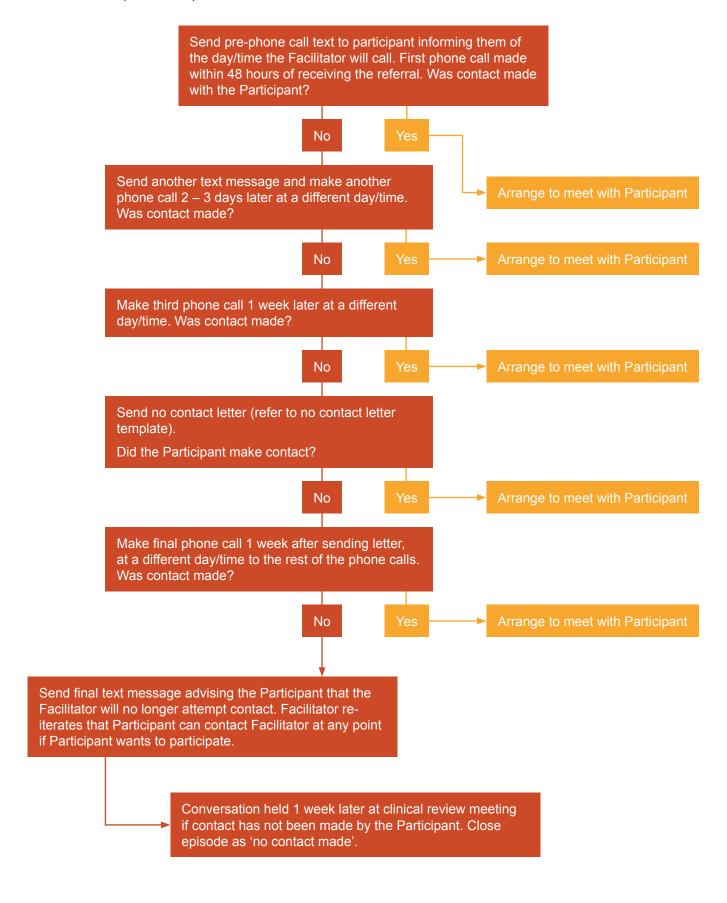
#### Goals

| 1. |  |
|----|--|
| 2. |  |
| 3. |  |

|        | Actions | By who |
|--------|---------|--------|
| Goal 1 |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
| Goal 2 |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
| Goal 3 |         |        |
| Coaro  |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |
|        |         |        |

## 7. No Contact Made

A Participant may be closed as "no contact made" if a Facilitator has made several attempts to make contact, however, has been unsuccessful each time.



#### No Contact Letter



DATE

FIRST & LAST NAME
ADDRESS

SUBURB, STATE & POSTCODE

#### Contact details

Cultural Pathways Program Wardliparingga Aboriginal Health Equity Theme, SAHMRI

Address:

North Terrace, Adelaide 5000

Facilitators:

Peita: 0436 681 488 Luke: 0436 680 071

Email: pathwaysprogram@sahmri.com

#### Dear PARTICIPANTS NAME,

I am writing to you regarding your interest in being involved in the Cultural Pathways Program. I have called the number you provided the Aboriginal Diabetes Study team to discuss the Program with you. However, I have been unable to get in contact with you.

I have enclosed some information for you to read through so that you are a little more aware of the Cultural Pathways Program.

If you have any questions or you are interested in being a part of the Cultural Pathways Program, please feel free to contact myself on the number above so we can organise a time to meet.

Sincerely,

**FACILITATORS NAME** 

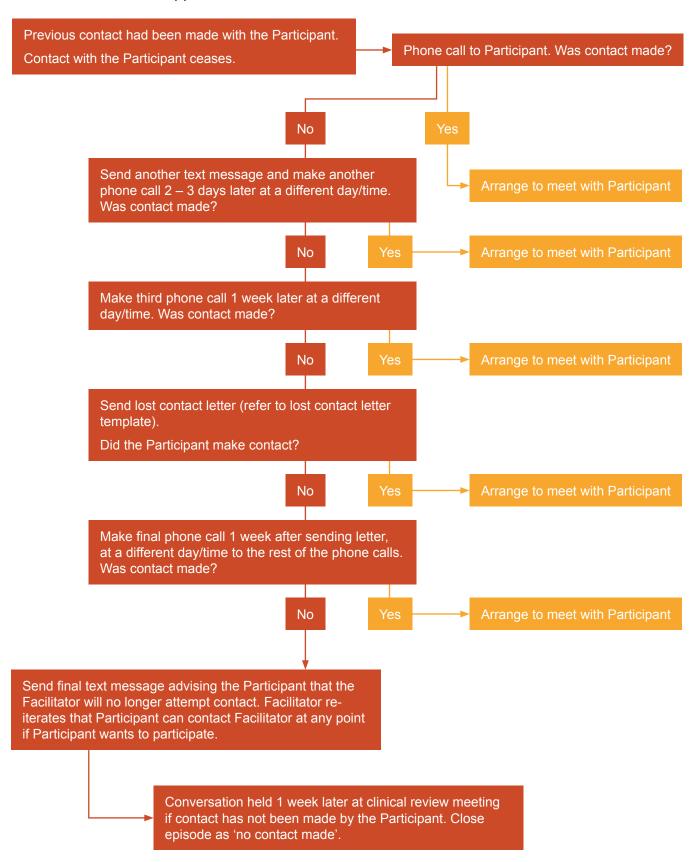
**Cultural Pathways Program** 

Wardliparingga Aboriginal Health Equity

South Australian Health & Medical Research Institute

## 8. Lost Contact

A Participant may be closed as "lost contact" if previous contact had been established with a Participant, however the Participant no longer returns the Facilitators phone calls/texts/emails or attends scheduled appointments.



#### Lost Contact Letter



#### Contact details

Cultural Pathways Program Wardliparingga Aboriginal Health Equity Theme, SAHMRI

Address:

North Terrace, Adelaide 5000

Facilitators:

Peita: 0436 681 488 Luke: 0436 680 071

Email: pathwaysprogram@sahmri.com

FIRST & LAST NAME
ADDRESS
SUBURB, STATE & POSTCODE

#### Dear PARTICIPANTS NAME,

I am writing to you regarding your involvement in our Cultural Pathways Program. I would like to acknowledge your willingness to participate in our program, and I really appreciate the time and effort you have given when talking with me.

I have attempted to contact you several times on your mobile, however I have been unable to reach you. Please feel free to contact me on the number above and let me know if you would or would not like to continue being involved in the program.

If you have changed your contact details recently, feel free to call me and update your information.

Sincerely,

**FACILITATORS NAME** 

Program Facilitator

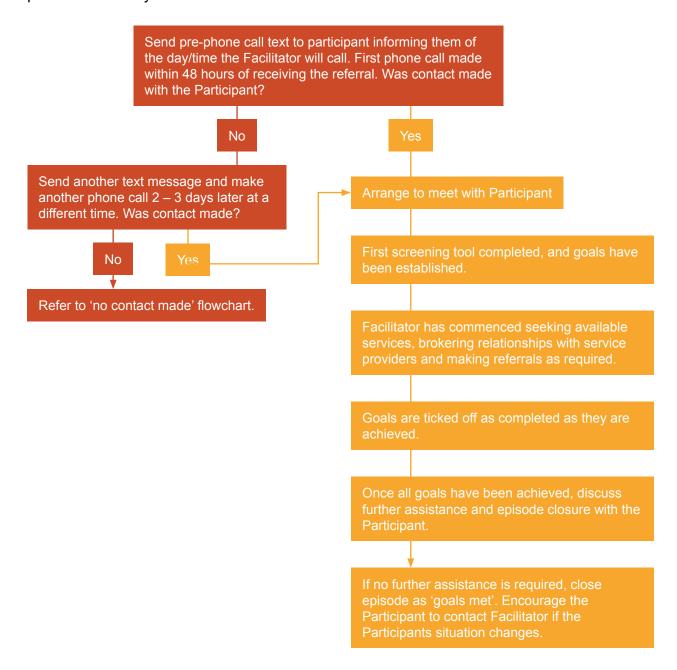
**Cultural Pathways Program** 

Wardliparingga Aboriginal Health Equity

South Australian Health & Medical Research Institute

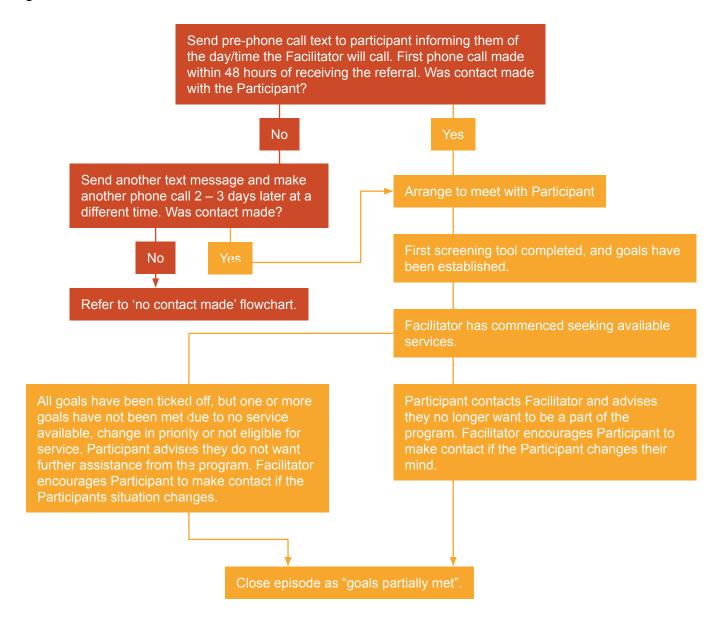
## 9. Goals Met

A Participant may be closed as "goals met" when all identified goals have been met and the Participant declines any further assistance.



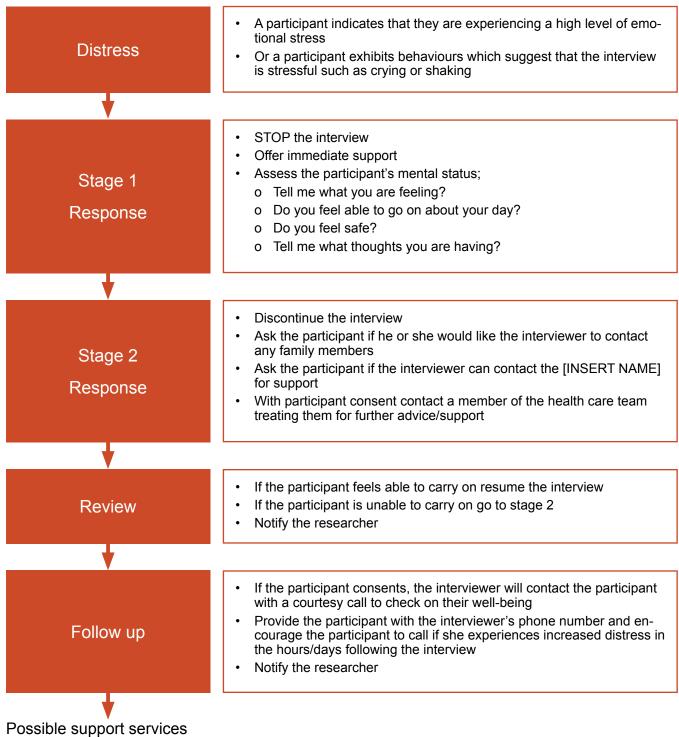
## 10. Goals Partially Met

A Participant may be closed as "goals partially met" on two occasions. Firstly, if the Participant has all goals ticked off, however not all goals have been met due to no service available, change in priority or not eligible for service. Or secondly if the Participant contacts the Facilitator and states they no longer want to be a part of the program, however, one or more goals have been met.



## 11. Distress Protocol

Distress Protocol for participants for the Pathways Program (For Facilitators of the Pathways Program use ONLY)



| Reception   | ADDRESS: 182-190 Wakefield Street, Adelaide SA 5000                                   | Tel: (08) 8406 1600 |
|---|---|---------------------|
| Nunkuwarrin Yunti   | Reception will be able to refer the participant for long term counselling and support |                     |
| Contact the researcher who will assist in taking appropriate action to care for the [participant] | Prof Alex Brown (email) Dr Natasha Howard, Platform Lead (email)                      |                     |

Note: The researchers are required to notify possible support services and ensure support as per their mandate throughout the course of the research project.

## 12. ISBAR Guidelines

An ISBAR entry is completed after the first face to face contact has been held with a new participant. An ISBAR entry is used as a clinical handover tool and more specifically for the program, provides an introduction of the new participant.

#### **General Guidelines**

Client records are legal documents, and as such, they represent the quality of service provided by the Facilitator.

Case notes should be documented as soon as possible following the session as to avoid uncertainties, confusions and recall errors (within 24 hours).

Make sure entries are legible, and free from grammatical and spelling errors.

Documentation should reflect the Facilitators level of training (scope) and not seek to diagnose or steer from the purpose of recording the case notes.

Case notes should not include information that is not relevant to the "Pathways Program's" purpose (guidelines and framework).

All entries should be signed off after the plan, with Facilitators full name and title e.g. first name, last name, Program Facilitator.

Specific terms that are regularly used when documenting can be abbreviated, to ensure consistency in each entry, see data dictionary below for a list of terms that can be abbreviated.

| TERM | DEFINITION                |  |
|------|---------------------------|--|
| CPP  | Cultural Pathways Program |  |
| F    | Facilitator               |  |
| Pt   | Participant               |  |

#### **Example of an ISBAR entry:**

Face to Face meeting held with Participant in Participant's home. Present: Facilitator and Participant. Conversation held with Participant re: Cultural Pathways program and process of working with Facilitator to set goals and work towards achieving the goals. Participant agreed to complete intake process and become an active Participant in the program. No previous episodes with the program.

Participant is a 54-year-old Aboriginal man, living in the metro south area. Participant appears stated age, dressed appropriately for the weather at time of meeting. No obvious signs of distress, speech not pressured. Participant engaged freely in conversation with Facilitator.

Conversation held re: consenting for research process. Facilitator explained research process- only parts of Participant story would be used, provided examples of research component the program would report e.g. areas requiring assistance, number of sessions with Participant, services talked to etc. Participant stated that he was uncertain if he wanted to be involved in research process. Facilitator explained that Participant could choose not to be involved in research process but could still work with Facilitator to seek assistance to achieve goals. Facilitator stated that Participant could think about the research process and make a decision regarding the process at the next session.

Participant provided personal details for registration process and completed first screening tool with Facilitator- see screening tool. Areas for further follow up included health, family issues, community connectiveness, behaviour that are no good and opportunities to learn and share about Aboriginal culture. Participant stated that he was recently involved in a major car accident and had an impatient stay as a result. Participant further stated that he has ongoing outpatient appointments to attend.

Facilitator informed Participant of follow up sessions and goal setting process.

P/ Next session arranged for [date and time].

Facilitator to complete Comprehensive screening tool with participant

Facilitator to discuss research process with Participant at next session.

First Name last name- Program facilitator.

The following is a break down of the ISBAR entry and what should be documented to address each section.

#### Identify

Document what type of contact occurred, where the event took place, who was present. In the Identify section, document any conversations held regarding program expectations. Provide a summary of the Participant, age, location, cultural status, observation from first session.

Face to Face meeting held with Participant in Participant's home. Present: Facilitator and Participant. Conversation held with Participant re: Cultural Pathways program and process of working with Facilitator to set goals and work towards achieving the goals. Participant agreed to complete intake process and become an active Participant in the program.

Participant is a 54-year-old Aboriginal man, living in the metro south area. Participant appears stated age, dressed appropriately for the weather at time of meeting. No obvious signs of distress, speech not pressured. Participant engaged freely in conversation with Facilitator.

#### **Situation**

Document the reason for the session.

Participant provided personal details for registration process and completed first screen-ing tool with Facilitator- see screening tool.

Conversation held re: consenting for research process. Facilitator explained research process- only parts of Participant story would be used, provided examples of research component the program would report e.g. areas requiring assistance, number of sessions with Participant, services talked to etc. Participant stated that he was uncertain if he wanted to be involved in research process. Facilitator explained that Participant could choose not to be involved in research process but could still work with Facilitator to seek assistance to achieve goals. Facilitator stated that Participant could think about the research process and make a decision regarding the process at the next session.

#### Background

Document any relevant history e.g. previous episodes with the program. Anything the Participant discloses during first session, potential risks, episodes of care (hospitalisation, imprisonment), major events.

No previous episodes with the program.

Participant stated that he was recently involved in a major car accident and had an impatient stay as a result. Participant further stated that he has ongoing outpatient appointments to attend.

#### Assessment

Document any areas the Participant identifies as priority or needs. Any assessment of Participant carried out by Facilitator.

Areas for further follow up included health, family issues, community connectiveness, behaviour that are no good and opportunities to learn and share about Aboriginal culture. Facilitator informed Participant of follow up sessions and goal setting process.

#### Recommendation

Document any actions required to be carried out by either Facilitator or Participant

P/ Next session arranged for [date and time].

Facilitator to complete Comprehensive screening tool with participant

Facilitator to discuss research process with Participant at next session.

First Name last name- Program facilitator

## 13. SOAP Guidelines

A SOAP note entry documents progression, and is required after any interaction with, or for, the participant has occurred. For example - phone call, home visit, meeting, correspondence.

#### General Guidelines

Client records are a legal document and represent the quality of service provided by the Facilitator.

Case notes should be recorded as soon as possible following the session as to avoid uncertainties, confusions and recall errors.

Make sure entries are legible, free from grammatical and spelling errors.

The client's record should reflect the Facilitators level of training and not seek to diagnose or steer from the purpose of the recording of case notes.

Case notes should not include information that is not relevant to the "Pathways Program's" purpose.

Amendments to case notes are to be avoided. If a mistake is made the Facilitator should make the correction without obstructing the mistake or leaving it illegible. Corrections can be made by indicating the mistake in closed brackets "( )" with the note "Error" and the recording Facilitators initials as well as the time and date.

All case notes should be signed off with a legal signature consisting of the Facilitators first initial, last name and legal signature.

Specific terms that are regularly used when documenting can be abbreviated to ensure consistency in each entry. See data dictionary below:

| TERM | DEFINITION                |
|------|---------------------------|
| CPP  | Cultural Pathways Program |
| F    | Facilitator               |
| Pt   | Participant               |
| P/c  | Phone Call                |
| H/v  | Home Visit                |
| Appt | Appointment               |
| P/   | Plan                      |

#### **Example of a SOAP Note:**

P/c made to Pt. F asked Pt if the financial counselling service had been in contact with Pt to arrange an appt. Pt informed F that she had made the appt for next Tuesday.

Pt explained that she is wanting to find an outdoor exercise group to join, but it not sure where to look.

P/ F to contact Pt Tuesday afternoon F to research outdoor exercise groups F first name last name Program Facilitator The following is what should be documented to address each section:

#### **Subjective**

Document what the participant is saying regarding the causes, duration and seriousness of the issues they're facing. If the participant is facing multiple needs in various domains, document these in order of the participants self-identified priorities. Examples include:

- Describe what type of contact has occurred, location, people present, etc
- Any changes of the issue/s from the last session from the participants perspective?
- · Have any other issues arisen?
- Briefly, have the actions from the previous session been achieved?

Notes should be concise and to the point and avoid long quotations.

#### **Objective**

Document observations of the participant's behaviour during the session. Information may include verbal and non-verbal communication if face to face (eye contact, voice tone/volume or body language). Note any changes when they occur.

Facilitators observations should be written in a precise and descriptive way and within the training level of the Facilitator. Avoid making assumptions, rather describe the situation observed.

#### **Assessment**

The assessment is guided by the participants self-identified priority areas and the objective observation. The assessment should include details of the progress towards the objectives established in the previous session including any objectives that have been met since the previous session.

The assessment should identify themes or patterns within the session and should inform the next steps or 'plans' for future sessions. The assessment may include revisiting plans from the previous session to identify any progress or need for further action. At no point should Facilitators make a diagnosis or suggest treatment options.

#### **Plan**

The plan component is to include the steps to be taken after the session has ended and before the scheduling of the next session. This can include:

- Any relevant contacts that will need to be made on the part of the Facilitator or participant
- Actions to be followed around linking the participant to services

No previous actions should be included in the plan, though it may include repeat or follow up actions if objectives were not achieved from the previous session.

## 14. Data Entry Protocol

#### **Documentation Requirements**

All interactions and contact with participants and stakeholders (text message, phone call, face to face, email) must be recorded in the participants episode on the database REDCap. The first contact with participant will become the first SOAP note entry, and the first face to face is to be documented as an ISBAR entry (see documenting contacts below for more information). All contact with participants must be recorded no later than 24 hours after the contact has taken place.

Documentation of contact with stakeholders/other agencies and copies of emails and correspondence will be uploaded into REDCap within the participants episode record.

#### How to access the REDCap database

REDCap is a secure web application designed for managing online databases which can be accessed at www.redcap.sahmri.com.

The database requires a log-on ID to access the system and various levels of access will be given to team members as required. REDCap is the database system the Pathways Program will use to store all data collected from engagement with participants. The database was built specifically for the program using different pages (these pages are referred to as instruments) to capture data such as participant's personal details, assessment tools, case notes and goal prioritisation. Documents and correspondence can also be uploaded to the database, and progress reports will be generated from the database.

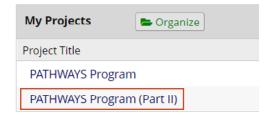
### **Data Entry**

#### Logging into REDCap

Logging on to REDCap requires a username of firstname.lastname and a password of your choice:



Once logged in, select 'Pathways Program (Part II)' and this will direct you to the most current program database. If you are working on more than one program, all programs would be listed here:



#### Registering new participants on REDCap

When the program receives new referrals, Facilitators are required to create a new episode on the database for each referral received. This process involves entering as much information about the participant as possible at the time of referral (refer below for what details to include for the registration).

1. To create a new entry, select Add/ Edit Records from the menu:



2. Facilitators are to allocate the referral an identification number e.g. CPP001, CPP002, etc. The database will display the previous CPP number, so you know the next sequential number:



3. Once the referral has been allocated an identification number, the Facilitator inputs all known details about the referral into the corresponding instruments listed below:



Please note, not all details will be known at the time of the referral, however the following actions must be taken to complete the registration process for a new participant episode.

| Instrument                     | Action  |
|--------------------------------|---|
| Participant ID                 | <ul> <li>→ Allocate participant a CPP number</li> <li>→ Select episode number</li> <li>→ Allocate a Facilitator to the participant</li> </ul> |
| Group / Community Intervention | → If working with an individual, select 'Individual' from the<br>Demographic variable   |
| Participant Information        | → Using the referral letter, enter details for as many variables as possible  |
| Participant Status             | → Click 'active participant' to open the episode  |

#### **Participant ID**

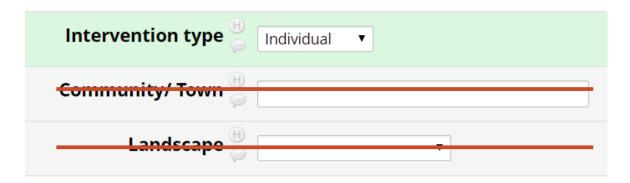
The first instrument on REDCap is Participant ID. Using the drop-down boxes, the Facilitator will allocate the participate an episode number and choose the name of the Facilitator. If the participant is new to the program, their episode number will be '1st'. If the participant is a returning referral, their episode number will be either 2<sup>nd</sup> or 3<sup>rd</sup> depending on how many times they have returned to the program.



#### **Group/Community Intervention**

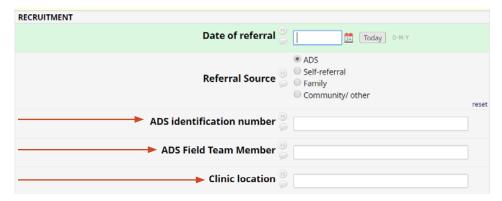
The second instrument allows the Facilitator to record whether they are working with an individual, group or community. If the Facilitator is working with an individual, they select 'individual' in the drop-down box. If the Facilitator is working with a group or community, they are to select 'group' or 'community' from the drop-down box and fill out the required details.

What the page looks like when 'individual' is selected:



#### **Aboriginal Diabetes Study Referrals**

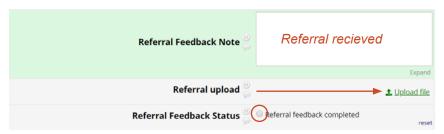
When a referral is received, the Facilitator is to record the date of referral and referral source. If the referral is received from the Aboriginal Diabetes Study (ADS), the Facilitator is required to document the referrals ADS identification number, referrers name and clinic location:



#### **Uploading Documentation**

The program database has an inbuilt function that provides an opportunity to upload and store documents in the database.

The referral upload variable provides an option to upload referral documents. If the referral is
presented as a hard copy document, the document needs to be scanned to upload into the participant's record. The Facilitator is to notify the referrer that the referral has been received and to write
"referral received" in the referral feedback note. Once that is completed, the Facilitator can check
off "referral feedback completed".



 After the participant has completed the Data Collection Form (see Data Collection Form appendix). and the evaluation consent form is signed, the form must be uploaded in the consent form – evaluation instrument and all relevant boxes ticked:

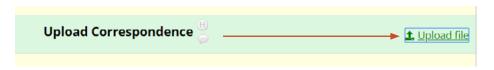


If the participant does not sign the evaluation consent form, the Facilitator is to click no for "consent form signed" and the participant is not to be included in the evaluation or for any future contact.

3. If an advocacy consent form is completed and signed, it is to be uploaded in the advocacy consent form instrument. The Facilitator is to also document what services/agencies the participant has given their consent for the Facilitator to contact:



4. Any other documents (support letters, income statements, etc) can be uploaded under correspondence:



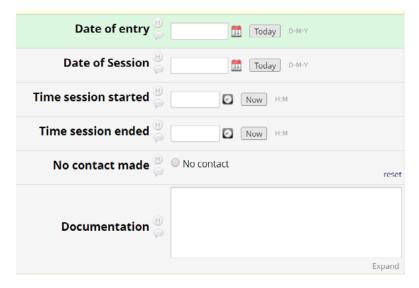
When uploading a referral, consent form, or any other document, it must be titled with the participants initials and then the type of document it is. For example:

- ADS referral PC ADS ref
- Evaluation consent form PC evalconsent
- Advocacy consent form PC advconsent
- Other documents PC incomestatement, PC housingsupport, etc

# **Documenting Contacts**

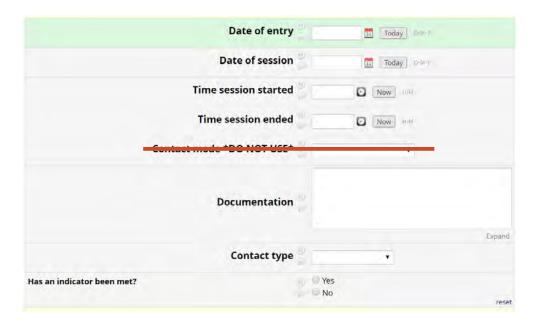
#### **ISBAR**

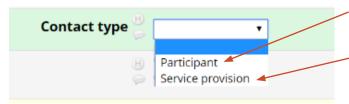
The first face to face meeting is to be recorded under the ISBAR Documentation instrument. The first face to face meeting will usually include the completion of the Data Collection Form. It is important the Facilitator records what domains the participant identified in the First Screening Tool, the goals the participant set and what actions are to be taken. This information is to be recorded in the "documentation" section. See ISBAR Guidelines and Example for more information.



# **SOAP Note**

A SOAP note is where every interaction with the participant (and service providers in relation to the participant) is recorded. A SOAP note layout is similar to an ISBAR; however, the Facilitator is required to select the contact type (participant or service provider) and then the mode of contact. Furthermore, the Facilitator must select if an indicator has been met. See SOAP note Guidelines and Example for more information.

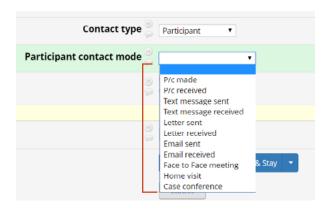




**Participant:** Selected when the Facilitator has had contact with the participant

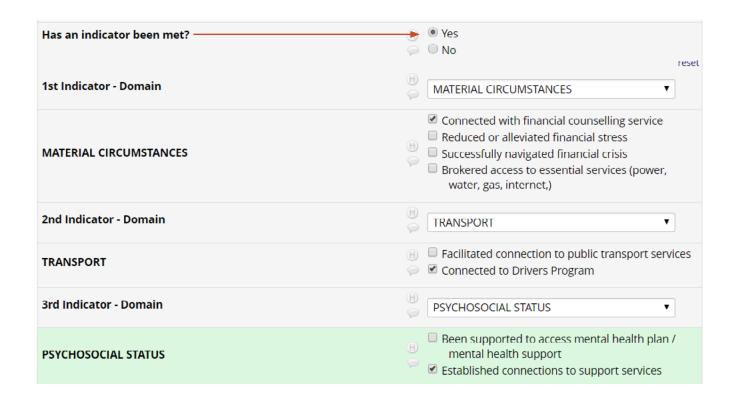
**Service Provision:** Selected when the Facilitator has been in contact with a service provider on behalf of, or in relation to the participant.

Once the contact type is selected, the Facilitator is to click on the drop-down box next to 'Participant Contact Mode' and select what mode of contact was used (phone call made, letter sent, etc). The contact mode options are the same for both participant and service provision.



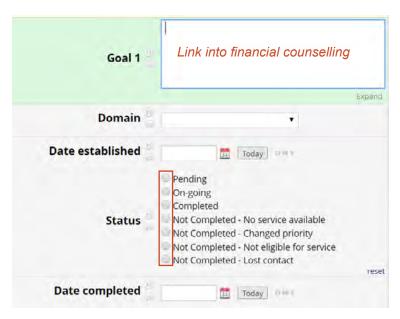
Lastly, the Facilitator is to identify whether an indicator has been met. An indicator is a measure for participant goal progress and can only be identified as 'met' if the participant confirms this is the case. If the Facilitator selects 'yes', the Facilitator can choose up to three indicators that have been addressed. The Facilitator is to select the drop-down box next to '1st, 2nd or 3nd Indicator Domain' to choose what domain the indicator is under. For more information on indicators, see *Wyatt Indicators & Examples*.

An example of what this may look if multiple indicators have been met:



# **Priority and Goal Setting**

Once the participant has established their goals, the goals are to be documented under the Priority and Goal Setting instrument. The participant's episode allows for a maximum of five goals to be recorded. The Facilitator is to record what the participants goal is, the date the goal was established, the domain the goal sits under and click 'on-going'. The goal is to remain 'ongoing' until either the participant states that is has been achieved, or it has not been completed for the 4 'not completed' reasons listed below. When a goal is no longer ongoing, the 'date completed' must be recorded. For more information on setting goals with participants, please see Priorities and Goals Framework and Guidelines.



# **Participant Status**

When the Facilitator opens a participant's episode, the participant status must be 'active'. This is achieved by clicking 'active participant' under the participant status instrument:



When closing the participants episode, 'active participant' is to be changed to 'participant case closed'. The Facilitator is to select the reason (no contact, lost contact, declined, goals met, goals partially met or withdrawn) for closure using the drop-down box, summarise why the episode has been closed and record the date of closure.



# **Completion of Entry**

After an entry in any instrument is completed, the Facilitator is to select 'complete' in the drop-down box at the bottom of the entry.



The Facilitator is to then select 'save and exit form' to exit the page, or 'save and stay' to save the entry but stay on the page. If the Facilitator selects 'cancel', any documentation completed in the entry will not be saved.



# 15. Program Indicators and Examples

| DOMAIN                    | INDICATOR  | EXAMPLE  |
|---------------------------|--|--|
| Material<br>Circumstances | Connected with a financial counselling service                             | Facilitator either refers the participant, or provides the participant with information about a financial counselling service and the participant makes contact with the service |
|                           | Reduced or alleviated financial stress                                     | Facilitator completes a Wyatt small grant application for a power bill; which is approved, ultimately reducing the Participants financial stress.                                |
|                           | Successfully navigated financial crisis                                    | Participant is linked in with a financial counsellor and manages to get a bill reduced through the process   |
|                           | Brokered access to essential services (power, water, gas, internet, phone) |  |
| Housing                   | Connected to housing services  | Participant completes and submits a housing application  |
|                           | Been provided information on housing services                              | Facilitator provides the participant with information about community housing and application forms  |
|                           | Been provided tenancy support  | Facilitator writes the participant a housing transfer support letter   |
| Employment/<br>Education  | Connected with education/ training opportunities                           | Participant engages in conversation with Job Active  |
|                           | Enrolled in education/training   | Participant enrols in a course at Tafe SA  |
|                           | Maintained engagement in education/training                                | Participant continues to go to their TAFE classes  |
|                           | Connected with mentoring/<br>professional development<br>initiatives       | Participant engages with a professional development initiative   |
|                           | Connected with work experience/voluntary activity opportunities            | Participant engages with work experience opportunities   |
|                           | Successfully obtained a scholarship  | Participant was successful in obtaining a scholarship to study at university   |
|                           | Connected with employment opportunities                                    |  |
|                           | Achieved full time/part time/<br>casual employment                         | Participant was successful in achieving employment   |
| Health & Medical          | Been referred to a health service/program                                  | Facilitator refers Participant to Uni SA physio  |
| Transport                 | Facilitated connection to public transport services                        | Facilitator provides Participant with contact information for Adelaide Metro about timetables. Participant makes contact with Adelaide Metro.                                    |
|                           | Connected to a drivers program   | Facilitator provides Participant with information about a driving program. Participant makes contact with the program  |

| DOMAIN                                 | INDICATOR   | EXAMPLE  |
|--|---|--|
| Food Security                          | Connected to Emergency Food Relief  | Facilitator refers Participant to their nearest<br>Salvation Army for food vouchers. Participant visits<br>Salvation Army    |
|  | Connected to Food Program/s (subsidised groceries/nutritious foods)                               | Facilitator provides information about a food program and participant either calls or visits the program                     |
| Cultural/Community<br>Connectedness    | Connected to local community services/groups/programs   | Facilitator provides Participant with information about a local gym group in Participants area. Participants attends a class |
|  | Had provision of information about how to find out more about language group/cultural connections | Facilitator emails Participant information about their language group and where the Participant can find further information |
|  | Connected to local community activities/events  | Facilitator provides Participant with information about an upcoming event. Participant attends the event                     |
| Safety                                 | Been referred to family violence services   | Facilitator refers Participant to a domestic violence counselling service  |
|  | Connected to legal services   | Facilitator provides Participant with the phone number to Legal Services Commission SA. Participant calls them               |
| Health Behaviours                      | Connected with smoking cessation program  | Facilitator provides Participant with information about Quitline. Participant makes contact with Quitline                    |
|  | Connected with drug and alcohol services/program  | Facilitator provides Participant with information about DASSA. Participant makes contact with DASSA                          |
|  | Connected with physical activity program/s  | Facilitator provides Participant with information about Strength for Life. Participant makes contact with Strength for Life  |
| Family/Relationships                   | Been referred to family support services  | Facilitator refers Participant to a parenting support group  |
|  | Been referred to family counselling services  | Facilitator refers Participant to family counselling   |
| Psychosocial<br>Status (Mental Health) | Been supported to access mental health plan/support   | Facilitator provides Participant with information about mental health plans and discusses how to access appropriate support  |
|  | Established connections to support services   | Facilitator provides Participant with information and referral forms to Sonder. Participant makes contact with Sonder        |

# APPENDIX 5.2: CULTURAL PATHWAYS PROGRAM DATA COLLECTION INSTRUMENTS AND DICTIONARY

# Cultural Pathways Program Participant Information Data Collection Instruments

| Instrument       | Variable         | Data Type | Format / Expression  |
|------------------|------------------|-----------|--|
| Date of referral | cpp_date_ref     |           |  |
| Referral source  | cpp_ref_source   | Numeric   | 1 (ADS) 2 (Self-Referral) 3 (Family) 4 (Community/Other)   |
| Gender           | cpp_gender       | Numeric   | 1 (Male) 2 (Female) 3 (Chosen not to Identify)   |
| Community/Town   | cpp_community    | Written   | [text]   |
| Postcode         | cpp_postcode     | Written   | [text]   |
| Landscape        | cpp_landscape3   | Numeric   | 1 "APY Lands" 2 "Remote Far North" 3 "Remote Far West" 4 "Whyalla" 5 "Port Augusta" 6 "South Eyre Peninsula" 7 "New York Peninsula" 8 "Riverland" 9 "Murray Barker Fleurieu Coorong" 10 "Rural South East" 11 "Outer North Metro" 12 "Inner North Metro" 13 "North East Metro" 14 "City East Metro" 15 "Port North West Metro" 16 "West Metro" 17 "Inner South Metro" 18 "Outer South Metro" 19 "Remainder of SA". |
| Language Group   | cpp_language_grp | Written   | [text]   |
|                  |                  |           |  |

# Cultural Pathways First Screening Tool Data Collection Instruments

| Instrument                    | Variable               | Data Type | Format / Expression |
|-------------------------------|------------------------|-----------|---------------------|
| Food Security Question        | cpp_food_security      | Numeric   | 1 (Yes)             |
|                               |                        |           | 2 (No)              |
| Material Circumstances        |                        |           |                     |
| Question                      | cpp_material_circ      |           |                     |
| Health Care Access            |                        |           |                     |
| Question                      | cpp_health_care_access |           |                     |
| Turana ant Occastica          |                        |           |                     |
| Transport Question            | cpp_transport          |           |                     |
| Housing Question              |                        |           |                     |
| Employment/Education          | cpp_housing            |           |                     |
| Employment/Education Question | cpp_emp_edu            |           |                     |
|                               | 112 12                 |           |                     |
| Literacy Question             | can literacy           |           |                     |
| Health Care Question          | cpp_literacy           |           |                     |
|                               | cpp_health             |           |                     |
| Psychosocial Question         | cpp_psych_soc_status   |           |                     |
| Family Question               | cpp_psycii_soc_status  |           |                     |
|                               | cpp_family             |           |                     |
| Community Connection          | cpp_comm_conn          |           |                     |
| Safety Question               | cpp_comm_com           |           |                     |
|                               | cpp_safety             |           |                     |
| Behavioural Question          | cpp_social             |           |                     |
| Culture Question              | opp_300.a.             |           |                     |
|                               | cpp_culture            |           |                     |
| Other Concerns Question       | cpp_other              |           |                     |
|                               |                        |           |                     |

# Cultural Pathways ISBAR Documentation Data Collection Instruments

| Instrument      | Variable      | Data Type | Format / Expression |
|-----------------|---------------|-----------|---------------------|
| Date of session | cpp_sess_dt   | Date      | Dd/mm/yy            |
| Documentation   | cpp_doc_isbar | Written   | [text]              |

# Cultural Pathways Priority and Goal Setting Data Collection Instrument

| Instrument       | Variable            | Data Type | Format / Expression  |
|------------------|---------------------|-----------|--|
| Goal 1           | cpp_goal_1          | Written   | 1 "Food Security"  |
| Domain'          | cpp_goal1_domain    | Numeric   | 2 "Material Circumstances" 3 "Health Care Access" 4 "Transport" 5 "Housing" 6 "Employment_Education" 7 "Literacy" 8 "Health" 9 "Psychosocial Status" 10 "Family" 11 "Community Connection" 12 "Safety" 13 "Social" 14 "Cultural" 15 "Other". |
| Date Established | cpp_date_est_goal1  | Date      | Dd/mm/yy   |
| Status           | cpp_status1         | Numeric   | 1 (Pending) 2 (On-Going) 3 (Completed) 4 (Not Completed - No service available) 5 (Not Completed - Changed priority) 6 (Not Completed - Not eligible for service) 7 (Not Completed - Lost contact)   |
| Date Completed   | cpp_date_comp_goal1 | Date      | Dd/mm/yy   |

# Cultural Pathways Progress Notes (SOAP) Data Collection Instrument

| Instrument             | Variable             | Data Type | Format / Expression                      |
|------------------------|----------------------|-----------|--|
| Date of session        | cpp_sess_dt_soap     | Date      | Dd/mm/yy                                 |
|                        |                      |           | , ,,,                                    |
| Time session started   | cpp_activity_started | Time      | 00:00am/pm                               |
| Time session ended     | cpp_activity_ended   | Time      | 00:00am/pm                               |
|                        |                      |           |  |
| Documentation          | cpp_doc_soap         | Written   | [text]                                   |
|                        |                      |           |  |
| Contact type           | cpp_soap_type        | Numeric   | 1 (Participant)                          |
|                        |                      |           | 2 (Service Provision)                    |
|                        |                      |           |  |
| Participant contact    | cpp_mode_soap_pt     | Numeric   | 1 (P/c made)                             |
| mode                   |                      |           | 2 (P/c received)                         |
|                        |                      |           | 3 (Text message sent)                    |
|                        |                      |           | 4 (Text message received)                |
|                        |                      |           | 5 (Letter sent)                          |
|                        |                      |           | 6 (Letter received)                      |
|                        |                      |           | 7 (Email sent)                           |
|                        |                      |           | 8 (Email received)                       |
|                        |                      |           | 9 (Face to face meeting)                 |
|                        |                      |           | 10 (Home visit)                          |
| Service contact mode   | cnn mode coan cn     | Numeric   | 11 (Case conference) 1 - 9 same as above |
| Service contact mode   | cpp_mode_soap_sp     | Numeric   | 10 (Case conference)                     |
|                        |                      |           | 11 (Referral received)                   |
|                        |                      |           | 12 (Referral sent)                       |
|                        |                      |           | 13 (Facilitation)                        |
|                        |                      |           | 15 (Facilitation)                        |
| P/c outcome            | cpp_phone_out        | Numeric   | 1 (Successful)                           |
| 170000000              | opp_pnone_out        | - ramene  | 2 (No contact made)                      |
|                        |                      |           | _ (110 001110001111000)                  |
| Attended session       | cpp attendance soap  | Numeric   | 1 (Yes)                                  |
|                        |                      |           | 0 (No)                                   |
|                        |                      |           |  |
| Indicator Met          | cpp_indicator_met    | Numeric   | 1 (Yes)                                  |
|                        | _                    |           | 2 (No)                                   |
|                        |                      |           |  |
| 1st Indicator - Domain | cpp_domain_ind       | Numeric   | 1 "Material Circumstances"               |
| 2nd Indicator - Domain | cpp_domain_ind2      |           | 2 "Housing"                              |
| 3rd Indicator – Domain | cpp_domain_ind3      |           | 3 "Employment/Education"                 |
|                        |                      |           | 4 "Health and Medical"                   |
|                        |                      |           | 5 "Transport"                            |
|                        |                      |           | 6 "Food Security"                        |
|                        |                      |           | 7 "Cultural/Community                    |
|                        |                      |           | Connectedness"                           |
|                        |                      |           | 8 "Safety"                               |
|                        |                      |           | 9 "Health Behaviours"                    |
|                        |                      |           | 10 "Family/Relationships"                |
|                        |                      |           | 11 "Psychosocial status".                |

|                        | 1                    | ·   |
|------------------------|----------------------|---|
|                        |                      |   |
| Material Circumstances | cpp_material_ind     | 1 (Connected with financial                           |
|                        |                      | counselling service)                                  |
|                        |                      | 2 (Reduced or alleviated financial stress)            |
| Housing                | cpp_housing_ind      | 3 (Successfully navigated                             |
|                        | obbo.ao8a            | financial crisis)                                     |
|                        |                      | 4 (Brokered access to                                 |
| Employment/Education   | cpp_emp_edu_ind      | essential services)                                   |
|                        |                      | 1 (Been provided tenancy                              |
|                        |                      | support)  |
|                        |                      | 2 (Been provided                                      |
|                        |                      | information on housing                                |
|                        |                      | services) 3 (Connected to housing                     |
|                        |                      | services)   |
|                        |                      | 1 (Connected with                                     |
|                        |                      | education/training                                    |
|                        |                      | opportunities)  |
|                        |                      | 2 (Enrolled in  |
|                        |                      | education/training)                                   |
|                        |                      | 3 (Maintained engagement                              |
|                        |                      | in education/training)                                |
|                        |                      | 4 (Connected with mentoring/professional              |
|                        |                      | development initiatives)                              |
|                        |                      | 5 (Connected with work                                |
|                        |                      | experience/voluntary                                  |
|                        |                      | activity opportunities)                               |
| Health and Medical     | cpp_health_med_ind   | 6 (Successfully obtained a                            |
|                        |                      | scholarship)  |
| Transport              | cpp_trans_ind        | 7 (Connected with                                     |
|                        |                      | employment opportunities) 8 (Achieved full-time/part- |
| Food Security          | cpp_food_sec_ind     | time/casual employment)                               |
| ,                      |                      | 1 (Been referred to a                                 |
|                        |                      | health service/program)                               |
|                        |                      | 1 (Facilitated connection to                          |
| Cultural/Community     | cpp_cult_comm_conn_i | public transport services)                            |
| Connectedness          | nd                   | 2 (Connected to a drivers                             |
|                        |                      | program) 1 (Connected to emergency                    |
|                        |                      | food relief)  |
|                        |                      | 2 (Connected to food                                  |
|                        |                      | program/s - subsidised                                |
| Safety                 |                      | groceries/nutritious foods)                           |
|                        | cpp_safety_ind       | 1 (Connected to local                                 |
| Haalah Dahasda         |                      | community/services/group                              |
| Health Behaviours      | onn health beh ind   | s/programs)   |
| L                      | cpp_health_beh_ind   |   |

|                      |                 | 2/11 1                     |
|----------------------|-----------------|----------------------------|
|                      |                 | 2 (Had provision of        |
|                      |                 | information about how to   |
|                      |                 | find out more about        |
|                      |                 | language group/cultural    |
| Family/Relationships |                 | connections)               |
|                      | cpp_fam_rel_ind | 3 (Connected to local      |
|                      |                 | community                  |
|                      |                 | activities/events)         |
| Psychosocial Status  |                 | 1 (Been referred to family |
|                      | cpp_psy_soc_ind | violence services)         |
|                      |                 | 2 (Connected to legal      |
|                      |                 | services)                  |
|                      |                 | 1 (Connected with smoking  |
|                      |                 | cessation program)         |
|                      |                 | 2 (Connected with drug     |
|                      |                 | and alcohol                |
|                      |                 | services/program)          |
|                      |                 | 3 (Connected with physical |
|                      |                 | activitiy/program/s)       |
|                      |                 | 1 (Been referred to family |
|                      |                 | support services)          |
|                      |                 | 2 (Been referred to family |
|                      |                 | counselling services)      |
|                      |                 | 1 (Been supported to       |
|                      |                 | access mental health       |
|                      |                 | plan/mental health         |
|                      |                 | support)                   |
|                      |                 | 2 (Established connections |
|                      |                 |                            |
|                      |                 | to support services)       |

| Instrument | Variable        | Data Type | Format / Expression         |
|------------|-----------------|-----------|-----------------------------|
| Reason for | cpp_reason      | Numeric   | 1 (No contact made)         |
| closure    |                 |           | 2 (Lost contact)            |
|            |                 |           | 3 (Declined to participate) |
|            |                 |           | 4 (Goals met)               |
|            |                 |           | 5 (Withdrawn)               |
|            |                 |           | 6 (Goals partial met)       |
|            |                 |           |                             |
| Summary    | cpp_sum         | Written   |                             |
|            |                 |           |                             |
|            | cpp_date_closed | [date]    |                             |
| Case       |                 |           |                             |
| closed     |                 |           |                             |

# Cultural Pathways Program Participant Information Data Collection Instruments

| Instrument       | Variable         | Data Type | Format / Expression  |
|------------------|------------------|-----------|--|
| Date of referral | cpp_date_ref     |           |  |
| Referral source  | cpp_ref_source   | Numeric   | 1 (ADS) 2 (Self-Referral) 3 (Family) 4 (Community/Other)   |
| Gender           | cpp_gender       | Numeric   | 1 (Male) 2 (Female) 3 (Chosen not to Identify)   |
| Community/Town   | cpp_community    | Written   | [text]   |
| Postcode         | cpp_postcode     | Written   | [text]   |
| Landscape        | cpp_landscape3   | Numeric   | 1 "APY Lands" 2 "Remote Far North" 3 "Remote Far West" 4 "Whyalla" 5 "Port Augusta" 6 "South Eyre Peninsula" 7 "New York Peninsula" 8 "Riverland" 9 "Murray Barker Fleurieu Coorong" 10 "Rural South East" 11 "Outer North Metro" 12 "Inner North Metro" 13 "North East Metro" 14 "City East Metro" 15 "Port North West Metro" 16 "West Metro" 17 "Inner South Metro" 18 "Outer South Metro" 19 "Remainder of SA". |
| Language Group   | cpp_language_grp | Written   | [text]   |
|                  |                  |           |  |

# Cultural Pathways First Screening Tool Data Collection Instruments

| Instrument                   | Variable               | Data Type | Format / Expression |
|------------------------------|------------------------|-----------|---------------------|
| Food Security Question       | cpp_food_security      | Numeric   | 1 (Yes)             |
|                              |                        |           | 2 (No)              |
| Material Circumstances       |                        |           |                     |
| Question                     | cpp_material_circ      |           |                     |
| Hardida Carra Arrana         |                        |           |                     |
| Health Care Access  Question | cpp_health_care_access |           |                     |
| Question                     | cpp_neartn_care_access |           |                     |
| Transport Question           |                        |           |                     |
| Haveing Overtice             | cpp_transport          |           |                     |
| Housing Question             | cpp_housing            |           |                     |
| Employment/Education         |                        |           |                     |
| Question                     | cpp_emp_edu            |           |                     |
| Literacy Question            |                        |           |                     |
| Literacy Question            | cpp_literacy           |           |                     |
| Health Care Question         |                        |           |                     |
| Davish associal Overstien    | cpp_health             |           |                     |
| Psychosocial Question        | cpp_psych_soc_status   |           |                     |
| Family Question              |                        |           |                     |
|                              | cpp_family             |           |                     |
| Community Connection         | cpp_comm_conn          |           |                     |
| Safety Question              | cpp_comm_com           |           |                     |
|                              | cpp_safety             |           |                     |
| Behavioural Question         | onn cooial             |           |                     |
| Culture Question             | cpp_social             |           |                     |
| <b>1</b>                     | cpp_culture            |           |                     |
| Other Concerns               |                        |           |                     |
| Question                     | cpp_other              |           |                     |

# Cultural Pathways ISBAR Documentation Data Collection Instruments

| Instrument      | Variable      | Data Type | Format / Expression |
|-----------------|---------------|-----------|---------------------|
| Date of session | cpp_sess_dt   | Date      | Dd/mm/yy            |
| Documentation   | cpp_doc_isbar | Written   | [text]              |

# Cultural Pathways Priority and Goal Setting Data Collection Instrument

| Instrument       | Variable            | Data Type | Format / Expression  |
|------------------|---------------------|-----------|--|
| Goal 1           | cpp_goal_1          | Written   | 1 "Food Security"  |
| Domain'          | cpp_goal1_domain    | Numeric   | 2 "Material Circumstances" 3 "Health Care Access" 4 "Transport" 5 "Housing" 6 "Employment_Education" 7 "Literacy" 8 "Health" 9 "Psychosocial Status" 10 "Family" 11 "Community Connection" 12 "Safety" 13 "Social" 14 "Cultural" 15 "Other". |
| Date Established | cpp_date_est_goal1  | Date      | Dd/mm/yy   |
| Status           | cpp_status1         | Numeric   | 1 (Pending) 2 (On-Going) 3 (Completed) 4 (Not Completed - No service available) 5 (Not Completed - Changed priority) 6 (Not Completed - Not eligible for service) 7 (Not Completed - Lost contact)   |
| Date Completed   | cpp_date_comp_goal1 | Date      | Dd/mm/yy   |

# Cultural Pathways Progress Notes (SOAP) Data Collection Instrument

| Instrument             | Variable             | Data Type | Format / Expression                |
|------------------------|----------------------|-----------|------------------------------------|
| Date of session        | cpp_sess_dt_soap     | Date      | Dd/mm/yy                           |
|                        |                      |           | , ,,,                              |
| Time session started   | cpp_activity_started | Time      | 00:00am/pm                         |
| Time session ended     | cpp_activity_ended   | Time      | 00:00am/pm                         |
|                        |                      |           |                                    |
| Documentation          | cpp_doc_soap         | Written   | [text]                             |
|                        |                      |           |                                    |
| Contact type           | cpp_soap_type        | Numeric   | 1 (Participant)                    |
|                        |                      |           | 2 (Service Provision)              |
|                        |                      |           |                                    |
| Participant contact    | cpp_mode_soap_pt     | Numeric   | 1 (P/c made)                       |
| mode                   |                      |           | 2 (P/c received)                   |
|                        |                      |           | 3 (Text message sent)              |
|                        |                      |           | 4 (Text message received)          |
|                        |                      |           | 5 (Letter sent)                    |
|                        |                      |           | 6 (Letter received) 7 (Email sent) |
|                        |                      |           | 8 (Email received)                 |
|                        |                      |           | 9 (Face to face meeting)           |
|                        |                      |           | 10 (Home visit)                    |
|                        |                      |           | 11 (Case conference)               |
| Service contact mode   | cpp_mode_soap_sp     | Numeric   | 1 - 9 same as above                |
|                        |                      |           | 10 (Case conference)               |
|                        |                      |           | 11 (Referral received)             |
|                        |                      |           | 12 (Referral sent)                 |
|                        |                      |           | 13 (Facilitation)                  |
|                        |                      |           |                                    |
| P/c outcome            | cpp_phone_out        | Numeric   | 1 (Successful)                     |
|                        |                      |           | 2 (No contact made)                |
|                        |                      |           |                                    |
| Attended session       | cpp_attendance_soap  | Numeric   | 1 (Yes)                            |
|                        |                      |           | 0 (No)                             |
| Indicator Mot          | one indicator mot    | Numaria   | 1 (Vos)                            |
| Indicator Met          | cpp_indicator_met    | Numeric   | 1 (Yes)<br>2 (No)                  |
|                        |                      |           | ∠ (IVO)                            |
| 1st Indicator - Domain | cpp_domain_ind       | Numeric   | 1 "Material Circumstances"         |
| 2nd Indicator - Domain | cpp_domain_ind2      |           | 2 "Housing"                        |
| 3rd Indicator – Domain | cpp domain ind3      |           | 3 "Employment/Education"           |
|                        |                      |           | 4 "Health and Medical"             |
|                        |                      |           | 5 "Transport"                      |
|                        |                      |           | 6 "Food Security"                  |
|                        |                      |           | 7 "Cultural/Community              |
|                        |                      |           | Connectedness"                     |
|                        |                      |           | 8 "Safety"                         |
|                        |                      |           | 9 "Health Behaviours"              |
|                        |                      |           | 10 "Family/Relationships"          |
|                        |                      |           | 11 "Psychosocial status".          |

|                        | 1                    | ·   |
|------------------------|----------------------|---|
|                        |                      |   |
| Material Circumstances | cpp_material_ind     | 1 (Connected with financial                           |
|                        |                      | counselling service)                                  |
|                        |                      | 2 (Reduced or alleviated financial stress)            |
| Housing                | cpp_housing_ind      | 3 (Successfully navigated                             |
|                        | obbo.ao8a            | financial crisis)                                     |
|                        |                      | 4 (Brokered access to                                 |
| Employment/Education   | cpp_emp_edu_ind      | essential services)                                   |
|                        |                      | 1 (Been provided tenancy                              |
|                        |                      | support)  |
|                        |                      | 2 (Been provided                                      |
|                        |                      | information on housing                                |
|                        |                      | services) 3 (Connected to housing                     |
|                        |                      | services)   |
|                        |                      | 1 (Connected with                                     |
|                        |                      | education/training                                    |
|                        |                      | opportunities)  |
|                        |                      | 2 (Enrolled in  |
|                        |                      | education/training)                                   |
|                        |                      | 3 (Maintained engagement                              |
|                        |                      | in education/training)                                |
|                        |                      | 4 (Connected with mentoring/professional              |
|                        |                      | development initiatives)                              |
|                        |                      | 5 (Connected with work                                |
|                        |                      | experience/voluntary                                  |
|                        |                      | activity opportunities)                               |
| Health and Medical     | cpp_health_med_ind   | 6 (Successfully obtained a                            |
|                        |                      | scholarship)  |
| Transport              | cpp_trans_ind        | 7 (Connected with                                     |
|                        |                      | employment opportunities) 8 (Achieved full-time/part- |
| Food Security          | cpp_food_sec_ind     | time/casual employment)                               |
| ,                      |                      | 1 (Been referred to a                                 |
|                        |                      | health service/program)                               |
|                        |                      | 1 (Facilitated connection to                          |
| Cultural/Community     | cpp_cult_comm_conn_i | public transport services)                            |
| Connectedness          | nd                   | 2 (Connected to a drivers                             |
|                        |                      | program) 1 (Connected to emergency                    |
|                        |                      | food relief)  |
|                        |                      | 2 (Connected to food                                  |
|                        |                      | program/s - subsidised                                |
| Safety                 |                      | groceries/nutritious foods)                           |
|                        | cpp_safety_ind       | 1 (Connected to local                                 |
| Haalah Dahasda         |                      | community/services/group                              |
| Health Behaviours      | onn health beh ind   | s/programs)   |
| L                      | cpp_health_beh_ind   |   |

|                         |                 | 2 (Had provision of        |
|-------------------------|-----------------|----------------------------|
|                         |                 | information about how to   |
|                         |                 | find out more about        |
|                         |                 | language group/cultural    |
| Family/Relationships    |                 | connections)               |
| Tanniy/ Kelationsinps   | cpp_fam_rel_ind | 3 (Connected to local      |
|                         | cpp_ram_rer_md  | community                  |
|                         |                 | 1                          |
| Davish as a sial Status |                 | activities/events)         |
| Psychosocial Status     |                 | 1 (Been referred to family |
|                         | cpp_psy_soc_ind | violence services)         |
|                         |                 | 2 (Connected to legal      |
|                         |                 | services)                  |
|                         |                 | 1 (Connected with smoking  |
|                         |                 | cessation program)         |
|                         |                 | 2 (Connected with drug     |
|                         |                 | and alcohol                |
|                         |                 | services/program)          |
|                         |                 | 3 (Connected with physical |
|                         |                 | activitiy/program/s)       |
|                         |                 | 1 (Been referred to family |
|                         |                 | support services)          |
|                         |                 | 2 (Been referred to family |
|                         |                 | counselling services)      |
|                         |                 | 1 (Been supported to       |
|                         |                 | access mental health       |
|                         |                 | plan/mental health         |
|                         |                 | support)                   |
|                         |                 | 2 (Established connections |
|                         |                 | to support services)       |

| Instrument | Variable        | Data Type | Format / Expression         |
|------------|-----------------|-----------|-----------------------------|
| Reason for | cpp_reason      | Numeric   | 1 (No contact made)         |
| closure    |                 |           | 2 (Lost contact)            |
|            |                 |           | 3 (Declined to participate) |
|            |                 |           | 4 (Goals met)               |
|            |                 |           | 5 (Withdrawn)               |
|            |                 |           | 6 (Goals partial met)       |
|            |                 |           |                             |
| Summary    | cpp_sum         | Written   |                             |
|            |                 |           |                             |
|            | cpp_date_closed | [date]    |                             |
| Case       |                 |           |                             |
| closed     |                 |           |                             |

APPENDIX 5.3: PUBLISHED MANUSCRIPT:
STRENGTHENING APPROACHES TO RESPOND TO
THE SOCIAL AND EMOTIONAL WELL-BEING NEEDS
OF ABORIGINAL AND TORRES STRAIT ISLANDER
PEOPLE: THE CULTURAL PATHWAYS PROGRAM

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## **Development**

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#### **Kev words:**

Aboriginal and Torres Strait Islander; case management; evidence-based practice; primary health care; social and emotional wellbeing; social determinants of health

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# Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the Cultural Pathways Program

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#### **Abstract**

Aboriginal and Torres Strait Islander holistic health represents the interconnection of social, emotional, spiritual and cultural factors on health and well-being. Social factors (education, employment, housing, transport, food and financial security) are internationally described and recognised as the social determinants of health. The social determinants of health are estimated to contribute to 34% of the overall burden of disease experienced by Aboriginal and Torres Strait Islander people. Primary health care services currently 'do what it takes' to address social and emotional well-being needs, including the social determinants of health, and require culturally relevant tools and processes for implementing coordinated and holistic responses. Drawing upon a research-setting pilot program, this manuscript outlines key elements encapsulating a strengths-based approach aimed at addressing Aboriginal and Torres Strait Islander holistic social and emotional well-being.

The Cultural Pathways Program is a response to community identified needs, designed and led by Aboriginal and Torres Strait Islander people and informed by holistic views of health. The program aims to identify holistic needs of Aboriginal and Torres Strait Islander people as the starting point to act on the social determinants of health. Facilitators implement strengths-based practice to identify social and cultural needs (e.g. cultural and community connection, food and financial security, housing, mental health, transport), engage in a goal setting process and broker connections with social and health services. An integrated culturally appropriate clinical supervision model enhances delivery of the program through reflective practice and shared decision making. These embedded approaches enable continuous review and improvement from a program and participant perspective. A developmental evaluation underpins program implementation and the proposed culturally relevant elements could be further tailored for delivery within primary health care services as part of routine care to strengthen systematic identification and response to social and emotional well-being needs.

#### Introduction

Aboriginal and Torres Strait Islander knowledge and wisdom has long recognised the role of social and cultural factors on health and well-being (Bartlett & Boffa, 2001). Aboriginal and Torres Strait Islander holistic health philosophy describes social and emotional well-being as the interconnection of social emotional, spiritual, cultural factors on health and wellness of not just individuals but communities (NAHSWP, 1989). Social and emotional well-being as conceptualised by Gee et al. (Dudgeon et al., 2014) recognises the ongoing influence of historical, political and social factors on health and social outcomes (Swan & Raphael, 1995; Raphael & Swan, 1997; Dudgeon et al., 2014; Paradies et al., 2015). These social factors (employment, education, housing, income and transport) are internationally described and recognised as the social determinants of health and are estimated to contribute to 34% of the overall burden of disease experienced by Aboriginal and Torres Strait Islander people (ABS, 2013). Both internationally and cross-culturally peer-reviewed literature has established associations, explored pathways and biological mechanisms providing a critical knowledge base on the role of social factors on health (Braveman et al., 2011). Despite these understandings, there is limited evidence on effective intervention strategies that address how these social factors influence health outcomes within the population (Bambra et al., 2010; Thornton et al., 2016; Alegría et al., 2018; Luchenski et al., 2018).

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Recent government consultations highlight the importance of self-determined and timely action on the social determinants of health for Aboriginal and Torres Strait Islander communities incorporating system responses that are coordinated, culturally relevant and strengths-based (Andermann, 2016; Commonwealth of Australia, 2017; Frier et al., 2020; Osborne et al., 2013). Health systems face challenges in responding to the complex nature of the social determinants of health with collaborations required across health and social services; nonetheless, the clinical frontline workforce have been recognised as a potential catalyst for change in any systems response (Andermann, 2016). Clinical workforce approaches that include screening clients for social and emotional well-being (which include the social determinants of health) facilitate the early identification and management of needs, planned and coordinated responses and the monitoring of progress and outcomes (Langham et al., 2017).

In a current context, Aboriginal Community Controlled Health Services (ACCHOs) and primary health care services are 'doing whatever it takes' to meet the social and emotional well-being needs of Aboriginal and Torres Strait Islander people which includes addressing the social determinants of health in service delivery (CREATE, 2020). Consultations with ACCHOs have highlighted key principles which inform holistic approaches to the social determinants of health including self-determination, accessible and culturally safe care and strong partnerships that support clients to navigate social services (CREATE, 2020). A recent document analysis of 67 ACCHO annual reports found that all services were working to improve clients' intermediary social determinants of health, specifically material circumstances, biological, behavioural and psychosocial factors (Pearson et al., 2020). Whilst structured and funded Aboriginal and Torres Strait Islander health assessments for preventative care are widely implemented, these assessments are limited by a biomedical focus that inadequately addresses social and cultural factors (Bailie et al., 2019). Across organisations there are varied responses depending on the capacity (i.e. workforce, skills, training and resources) of the primary health care service (CREATE, 2020; Andermann, 2018). Furthermore, service delivery protocols for addressing the social determinants of health and more broadly data systems for monitoring their actions are not well established (Golembiewski et al., 2019; Osborne et al., 2013).

Strengths-based, person centred and empowerment approaches are often used synonymously to describe the delivery of health care for Aboriginal and Torres Strait Islander people. These approaches promote individuals control over their own lives and focus on abilities and resources to enable self-determination (Bovill et al., 2019; Gibson et al., 2020; Saleebey, 1996). Aboriginal and Torres Strait Islander people who have increased control and mastery over their lived experiences are empowered in their engagement with social and health services (Tsey et al., 2010). Health care services commonly describe intentions to deliver strengths-based approaches, yet the practical and genuine implementation with Aboriginal and Torres Strait Islander people is still emerging in practice (Askew et al., 2020; Gibson et al., 2020). Holistic case management models are well suited for strengths-based practice which focuses on empowering people to take charge of their own lives and to support the identification of existing strengths and resources (Saleebey, 1996). Case management approaches whilst diverse across disciplines and in different contexts usually include the following core functions; assessment, planning, linking, monitoring, advocacy and outreach services (Huber, 2002). Case management approaches in primary health care with Aboriginal

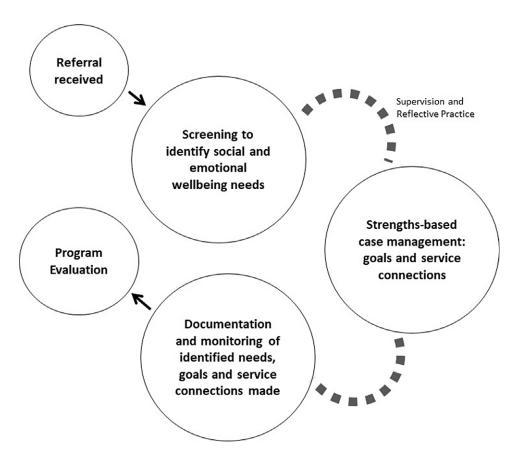
and Torres Strait Islander people report improvements in self-rated health status, reduction in depression and improved measures of diabetes control (Askew *et al.*, 2015). These findings suggest that patient-led case management has the potential to enhance holistic approaches to social and emotional well-being (Askew *et al.*, 2015).

The effects of colonisation and the continuing social and political oppression and dispossession of Aboriginal and Torres Strait Islander communities have contributed to significant socioeconomic and health inequities (Gracey & King, 2009). Persistent and disproportionate inequalities experienced by Aboriginal and Torres Strait Islander people highlight the need to better understand and respond to social and emotional well-being needs which includes the social determinants of health. There is a pressing need for coordinated best practice responses to social and emotional well-being screening and management, dedicated resources, training and ongoing monitoring (Langham et al., 2017). Existing evidence has not yet described approaches that collectively inform health care responses for Aboriginal and Torres Strait Islander social and emotional well-being. To address this gap, a pilot program has been designed within a research setting and includes the following key elements: i) identifying unmet needs, ii) strengths-based case management, iii) document and monitoring, iv) culturally relevant supervision and v) evaluation. The aim of this manuscript is to describe and critically explore the program's key elements from an Aboriginal and Torres Strait Islander perspective as part of strengthening practice-based evidence on social and emotional well-being.

#### **Discussion**

#### Program context

The Cultural Pathways program is implemented Wardliparingga Aboriginal Health Equity research team in the South Australian Health and Medical Research Institute, Adelaide, South Australia. Wardliparingga undertakes research that is of relevance to South Australian Aboriginal and Torres Strait Islander communities through partnerships, collaboration, respect, reciprocity and for the benefit of community (SAHMRI, 2014). The Cultural Pathways Program is designed and implemented by Aboriginal and Torres Strait Islander people as a response to community identified needs. The program is implemented within an Indigenous methodological framework and from inception to implementation the program has been underpinned by Aboriginal and Torres Strait Islander ways of knowing, being and doing (Rigney, 1999; Martin & Mirraboopa, 2003; Saunders et al., 2010; Wilson, 2011; Smith, 2012). Priority areas for research were established through extensive consultation and engagement with the community (King & Brown, 2015). All programs of work implemented by Wardliparingga have Aboriginal and Torres Strait Islander leadership and governance, through these structures the community consistently highlighted that more holistic responses, which included the social determinants of health, were required. The research team is predominantly Aboriginal and Torres Strait Islander researchers who bring wisdom and experience to the development of the program approach and implementation ensuring consistent alignment with Aboriginal and Torres Strait Islander ways of knowing, being and doing. The program described in this manuscript was approved by the Aboriginal Health Research Ethics Committee of South Australia (AHREC-04-17-733).



**Figure 1.** Cultural Pathways Program elements for responding to Aboriginal and Torres Strait Islander social and emotional well-being.

The program approach includes comprehensive screening utilising a specifically developed holistic screening tool to identify unmet social and emotional well-being needs. Following screening, facilitators implement strengths-based case management through goal setting, prioritisation and brokering connections to services. program structures embed documentation and monitoring of the program's social and emotional well-being responses, actions taken to address needs and outcomes for participants. These elements are underpinned by culturally relevant supervision, reflective practice and evaluation. The program approach critically explores the benefits, cultural relevance and responsiveness of common practices in case management. Through a combined understanding of these approaches, the program seeks to inform the evidence base for strengthened and coordinated responses to Aboriginal and Torres Strait Islander social and emotional well-being.

Program delivery is undertaken by male and female facilitators with workforce roles informed by a navigator approach, to assist individuals' engagement with the health care system and to overcome any barriers to care (Bernardes et al., 2018; Henderson & Kendall, 2011; Whop et al., 2012). Referrals are received from a large-scale population-based biomedical cohort study of Aboriginal and Torres Strait Islander South Australians. As part of the study, all participants receive a comprehensive health assessment that includes questions regarding their social and emotional well-being. Further to this, community engagement and consultations highlighted that post-study follow-up responses for participants would require addressing social and emotional well-being needs such as psychosocial health, financial literacy, food security and material circumstances. Participants are offered a referral to the Cultural Pathways Program, if unmet social and cultural needs

are identified during the assessment. The implementation setting replicates real-world service delivery models where presentation may initially be for a physical health need. Upon receipt of referrals from the study team, the Cultural Pathways Program facilitators connect with participants and implement the flexible participant led case management process (Figure 1).

Program elements informing a social and emotional well-being response have been detailed within the following sections, providing the theoretical underpinnings, Cultural Pathways Program approach, embedded Aboriginal and Torres Strait Islander ways of working and opportunities for strengthening practice.

#### Identifying unmet needs

Screening and assessment is a common first point of engagement in health settings and appropriate screening delivered as part of routine practice can enhance the timely and effective identification of needs and accordingly inform responses or prompt a more comprehensive assessment (Andermann, 2018). Indigenous specific health assessments are associated with improved preventive care for a range of health needs; however, a greater focus is needed on social and cultural factors (Bailie et al., 2019; Langham et al., 2017). Cultural Pathways Program facilitators implement a modified Social Needs Screening Tool (Health Leads 2016) to identify unmet social needs of participants. Developed through an Aboriginal and Torres Strait Islander researcher led process, with community input to ensure cultural relevance and responsiveness, the adapted holistic tool covers well-being domains including mental health and cultural and community connection and social domains including financial and food security, transport, employment, housing and social isolation. The

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process of cultural development ensures the questions are relevant, asked the right way, with cultural meaning and are best able to identify the unique needs of Aboriginal and Torres Strait Islander participants (Brown *et al.*, 2013; Langham *et al.*, 2017). Screening processes for the social determinants must be accompanied by plans for action (Gottlieb *et al.*, 2016; Davidson & McGinn, 2019), and as part of the program's case management approach the screening process assists the Facilitator to understand participant needs and enables the identification and prioritisation of participant goals. By implementing a structured and consistent approach, identifying and documenting unmet needs enable the measurement of actions, activities and the monitoring of participant outcomes.

#### Strengths-Based case management

The program's case management approach includes goal setting, prioritisation and brokering connections to services. Facilitators work in partnership with participants and tailor responses to individual circumstances and needs. A strengthsbased approach to case management ensures facilitators focus on clients' abilities, talents and resources to enable client's self-determination skills, develop resilience and the ability to respond or navigate similar situations in the future (Saleebey, 1996). Goal setting is a common step in the case of management process (Kisthardt et al., 1992) with theoretical concepts highlighting the importance of collaboration for effective goal setting (Vanpuymbrouck, 2014). An individuals' sense of control and autonomy influence their willingness to set goals and efforts for achieving them (Vieira & Grantham, 2011). The Australian Integrated Mental Health Initiative (AIMhi) is an existing framework that uses strengths based story telling (Nagel & Thompson, 2007). The Cultural Pathways Program implements a goal and priority setting framework utilising the AIMhi Pictorial Care Plan (Menzies School of Health Research, 2020) to explore physical, emotional, spiritual, cultural, family, social and work contexts to identify worries, strengths and resources. Consistent with Aboriginal and Torres Strait Islander ways of working, facilitators work in partnership with participants to identify and prioritise issues of most importance that will support improved well-being. As part of the strengths-based, empowerment and person-centred approaches, participants define their own priorities contributing to enhanced autonomy, control and self-efficacy.

As part of the 'brokering' approach to case management, facilitators connect participants with services to meet their needs. Making a referral to other services, organisations or agencies are widely implemented in health and social services. Social and emotional well-being and social determinants of health needs span across sectors with often multiple services and agencies involved, this requires coordination to minimise the burden on service users and to enable referrals and connections (Kowanko et al., 2009). Brokering connections relies on relationships, understandings of what is available across the breadth of health and social needs and understandings of culturally relevant services (McKenna et al., 2015; Treatment Center for Substance Abuse, 2000). To support this approach, facilitators undertake service mapping exercises to identify the available services and will pro-actively seek the most appropriate service to connect a participant to and reduce barriers to access these services (Huber, 2002). Facilitators actively support participants to access services by contacting services on behalf of participants, supporting participants when they contact

services themselves and follow up contact with participants to monitor progress. If necessary, facilitators address any challenges or barriers to support the best possible outcome. The active and coordinated approach to brokering connections enhances service access for participants and enables the program to also monitor brokerage outcomes.

#### **Documentation and monitoring**

Program monitoring involves measuring and reporting on progress and creates opportunities for continuous quality improvement (Hudson, 2016). Currently, health services rarely systematically collect data about or measure activity on the social determinants of health and require a mechanism to monitor and evaluate the impact of social and emotional well-being services they provide to address health outcomes (Langham et al., 2017; Reeve et al., 2015). Comprehensive understandings of the most appropriate measures for Aboriginal and Torres Strait Islander social and emotional well-being and the social determinants of health are still emerging. Existing national measures of well-being include psychological distress, positive well-being, anger, life stressors, discrimination, cultural identification and removal from natural family (AIHW, 2009). Measures for the social determinants of health as described by the World Health Organization (WHO) Conceptual Framework (Solar & Irwin, 2010) and outlined in the Aboriginal and Torres Strait Islander Health Performance Framework (AHMAC, 2017) include domains such as connection to country, education, employment, health system, housing, income and transport.

The Cultural Pathways Program combines social and emotional well-being and social determinants of health measures as part of the programs' monitoring framework. The program utilises REDCap (Research Electronic Data Capture), a secure web platform for managing online databases (Harris et al., 2009). The platform collects participant information, demographics and activity data which include when and how people are contacted and the services provided by social/health domain. The program measures factors such as unmet needs, identified goals, whether they have been achieved and the service connections made. The program utilises routine data for ongoing monitoring, quality improvement and as part of funding requirements and obligations. The data collected by the program was informed by Aboriginal and Torres Strait Islander understandings of health and well-being and the wisdom and expertise of the research team and community. The process included the collective development of culturally relevant measures in relation to social and emotional well-being, specifically practical ways to measure progress towards addressing complex social and cultural factors. This process enabled the program to capture information that is useful and relevant for Aboriginal and Torres Strait Islander people. A structured and consistent approach to identifying needs and a specifically designed monitoring framework enables the program to measure progress or outcomes which can be used to understand the needs of service users, to plan responses and to advocate for resources (Harfield et al., 2018).

## Culturally relevant supervision

Reflective practice and clinical supervision are recognised by many professions for their role in supporting enhanced clinical practice as well as the health and well-being of the workforce (Koivu *et al.*, 2012; Scerra, 2012; Thompson & Pascal, 2012). This is particularly important for Aboriginal and Torres

Strait Islander health workers and practitioners who have complex experiences including burnout and vicarious trauma (Nelson *et al.*, 2015). The Aboriginal and Torres Strait Islander health workforce and non-Indigenous workers in Aboriginal and Torres Strait Islander health contexts require access to high-quality cultural and clinical supervision which supports cultural safety, improved practice and well-being (Bainbridge et al., 2015; Truong et al., 2014). Available frameworks for culturally appropriate supervision with Aboriginal and Torres Strait Islander people include considerations for working with community, looking after self, understanding of roles and professional practice (Koivu et al., 2012; Nelson et al., 2015; Scerra, 2012; Victorian Aboriginal Child Care Agency (VACCA), 2013; Victorian Dual Diagnosis Education and Training Unit (VDDI), 2012). Despite the important role of culturally relevant clinical supervision in enhanced service delivery and the support and retention of the workforce in health care settings (AHCSA, 2020), evidence-based understanding of applied practice models are still emerging in peer reviewed evidence.

The Cultural Pathways Program utilises these existing frameworks as well as the knowledge and experience of program staff to implement a culturally relevant reflective practice and supervision model. An experienced Aboriginal clinician supports facilitators through a range of structures including weekly clinical yarning, one to one yarning and debriefing opportunities as required. Facilitators share perspectives, feelings, challenges, barriers and enablers in relation to both clinical practice as well as system, policy and organisational factors which impact the participant, Facilitator, or the program. Fundamentally, the supervision and reflective practice model are culturally grounded in relationships and yarning to support the cultural safety for Aboriginal and Torres Strait Islander participants whilst also enabling the retention and well-being of the Aboriginal and Torres Strait Islander workforce.

#### Developmental evaluation

Evaluating health programs and initiatives supports implementation across different contexts utilising insights into how and why they work and whether they have been effective (Lokuge et al., 2017). There is an increasing recognition of the important role of evidence-based programs featuring high quality and culturally relevant evaluation (Productivity Commission, 2019). The Cultural Pathways Program is underpinned by an Indigenous methodological evaluation framework which Developmental Evaluation, an approach to evaluation that supports innovation and adaptation in complex environments (Fagen et al., 2011; Patton, 2010), and is consistent with Indigenous methodology and participatory approaches requiring partnerships, trust and shared decision making (Gamble, 2008). The key to developmental evaluation is that the evaluator works with the team in real-time, asking evaluation questions, examining and tracking implications of adaptations and providing timely feedback as the program is implemented and modified or adapted as needed. The evaluator as an Aboriginal woman is immersed in as an insider drawing heavily on reflective practice and utilising the cultural knowledge and expertise of the evaluator as part of the evaluation method. The aim of the evaluation is to understand the process including what was delivered, how it was implemented and the experiences of program participants. The evaluation through reflective and formative methods supports further understanding on the interactions between facilitators, program

participants and the broader health and social service contexts. The evaluation framework includes community engagement, governance and approaches which have been purposely selected for their consistency with Indigenous methodologies. This framework ensures that the participation and voice of the community are therefore embedded throughout implementation to support tangible benefits to the community (SAHMRI, 2014).

#### **Conclusions**

There is a knowledge to action gap on how to assess and address the social determinants of health within clinical practice to inform the development of coordinated, culturally relevant and strength-based responses to meet the holistic social and emotional well-being needs of Aboriginal and Torres Strait Islander people and communities.

Primary health care services, often as the entry point for accessing health services, are well positioned to implement coordinated health equity responses which include addressing the social determinants of health (Pereira et al., 2017; Rasanathan et al., 2011). The absence of a readily applied model creates challenges for the provision of coordinated, resourced and systemic responses to the social determinants of health (CREATE, 2020). Routine screening for unmet needs, implementing strengths-based practice, connecting people to what they need, monitoring service provision and providing clinical and cultural support for the Aboriginal and Torres Strait Islander workforce align to existing practice and are transferable across contexts. Continuous quality improvement and monitoring enables primary health care services to embed new practices into services, systems and routines (Gardner et al., 2010).

The ability to implement holistic approaches to Aboriginal and Torres Strait Islander health through the intersection of health and social services requires adequate resources, training and support to clinical workforce (Andermann, 2016), including consideration of roles, responsibilities, scope of practice and readiness to implement strengths-based approaches. These changes cannot be implemented without addressing the ongoing impacts of racism and oppression of Aboriginal and Torres Strait Islander people, allowing for culturally safe systems which are able to meet holistic social and emotional well-being needs (Curtis *et al.*, 2019; Durey, 2010; Laverty *et al.*, 2017; Muise, 2019; Secombe *et al.*, 2019).

The Cultural Pathways Program builds on existing approaches to contribute to practice-based evidence of culturally relevant case management approaches which can be utilised as part of routine care to strengthen the systematic identification and response in primary health care delivery. The combined understandings of the elements outlined in this manuscript provide a framework to inform service planning and tailored implementation which can strengthen social and emotional well-being responses for Aboriginal and Torres Strait Islander people.

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**About the contributors.** Consistent with cultural protocol we position the contributors to this manuscript:

Tina Brodie is an Aboriginal woman with connections to Yawarrawarrka and Yandruwandha. She is a third year PhD Candidate at The University of Adelaide in the Faculty of Health and Medical Sciences and a Clinical

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Research Associate in Wardliparingga Aboriginal Health Equity, South Australian Health and Medical Institute. Her Research is exploring Aboriginal and Torres Strait Islander Social and Emotional Well-being, specifically the social determinants of health. Tina has over ten years of experience in Aboriginal and Torres Strait Islander Health in multiple clinical, project and leadership roles working with Aboriginal and Torres Strait Islander children and families. Tina has expertise in Indigenous methodologies and culturally responsive and ethical ways of working and engaging Aboriginal and Torres Strait Islander people and communities in research.

Odette Pearson is a Kuku Yalanji/Torres Strait Islander Population Health Platform Lead in Wardliparingga Aboriginal Research Unit at South Australian Health & Medical Research Institute. Her experience and post-doctoral training in Aboriginal health policy, health systems and inequity comprises a unique comprehensive skillset relevant to existing and emerging complexities of Aboriginal health and well-being. Specifically, Odette seeks to understand how institutional policies and practices drive health and social inequities experienced by Indigenous populations. Her novel approach is the use of community-level information to show and explore the reasons for variations in disadvantage both within the Aboriginal community and between the Aboriginal and non-Aboriginal community. Integral to her research is the inclusion of Aboriginal communities in defining their health and well-being and how Indigenous data can be governed in the future to derive greater benefit for the population.

Luke Cantley has family connections to the Gunditimara nation of Victoria and is a Research Associate located within Flinders University. Through his research, Luke is determined to solidify Aboriginal culture as a protective factor within the child protection system, whilst exploring the nuances between child safety and cultural safety. Luke holds extensive knowledge on the role unmet social and cultural needs have on positive health outcomes within the Aboriginal and Torres Strait Islander community and holds a strong passion for advocating for increased health care utilisation for health care consumers. Luke has gained extensive experience working as an Aboriginal Health Worker within a strengths-based approach across diverse sectors including Prison health, Primary Health Care, Public Housing and Mental Health Services. Developing expertise in 1) Culturally appropriate and ethical ways of engaging within the community, 2) Health and Well-being assessment methods fostering participatory action research, and 3) Social inequities generated by reduced access to services or resources.

Peita Cooper has a Bachelor of Social Work and currently works within the justice sector. Peita commenced as a Graduate in Wardliparingga Aboriginal Health Equity Theme, at the South Australian Health and Medical Research Institute (SAHMRI). As a Program Facilitator, Peita contributed to the delivery of strengths-based case management and developing culturally responsive practice with Aboriginal and Torres Strait Islander peoples' and communities. Her previous experience includes working in the disability sector.

Seth Westhead has family connections to the Awabakal and Wiradjuri nations of NSW and is a Research Associate with Wardliparingga Aboriginal Health Equity Theme, South Australian Health & Medical Research Institute. Through his research work, Seth strives to better understand how social and cultural determinants drive health and social inequities within society, particularly as it relates to the Indigenous population. He seeks to better equip communities and young people with tools and evidence for public health advocacy and enable communities to translate health research into meaningful action. Specifically, Seth has expertise in the: 1) conceptual development of Aboriginal specific social determinants and well-being frameworks and tools, 2) implementation of projects involving community engagement and community-led governance structures 2), and 3) undertaking of qualitative research methodologies and community and stakeholder participation interpretation of findings.

Alex Brown is an Aboriginal medical doctor and researcher, he is the Theme Leader of Wardliparingga Aboriginal Health Equity and Professor of Medicine at the University of Adelaide. He grew up on the south coast of New South Wales (NSW) with family connections to Nowra, Wreck Bay and Wallaga Lake on the far south coast of NSW. Over the last 20 years, Alex has established an extensive and unique research program focused on chronic disease in vulnerable communities, with a particular focus on outlining and overcoming health disparities. He leads projects encompassing epidemiology, psychosocial determinants of chronic disease, mixed methods health services research in

Aboriginal primary care and hospital settings, and randomised controlled trials of pharmacological and non-pharmacological chronic disease interventions. Alex has been heavily involved in engaging government and lead agencies in setting the agenda in Aboriginal cardiovascular disease management and control and chronic disease policy more broadly. He sits on a range of national committees, and co-chairs the Indigenous Research Health Fund through the MRFF.

Natasha Howard is the Wardliparingga Platform Lead: Implementation Science. The platform incorporates a systems view and privileges Indigenous knowledge to deliver mixed-method inter-disciplinary perspectives which aim to generate policy and practice-based evidence on the social determinants of health. Her experience spans both the health and social sciences, applying population approaches to investigate how the social and built environment enables and promotes cardiometabolic health and well-being, notably for priority populations. She has been active in advocacy and mentoring of the local population health community in both research and practice.

#### Conflict(s) of interest. None.

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# APPENDIX 5.4: CULTURAL PATHWAYS PROGRAM EVALUATION: INTERVIEW GUIDE

### **INTERVIEW GUIDE**

# Introduction and rapport:

- Thank you for taking the time to yarn with me today
- How are you feeling today? Are you keeping well?
- How have you found this year with all that has been happening...

# Today we are going to talk about:

- Your experiences with the Cultural Pathways Program
- How you found working with the facilitator
- The changes/impact the program made for you

Before we get started, I wanted to confirm you are okay with me recording our yarn today – if not that's okay I can take some notes as we talk.

I want to make this yarn as easy for you as I can and if at any time you would like to stop or there is something you prefer not to answer or talk about that is completely fine, just let me know, we can stop at any time or we can move on to yarn about something else.

When we first met you in [date] we went through some questions with to identify needs. Would you like to go through the screening tool again to see how things are going for you now?

#### Proceed to interview:

I have a few things I am really interested in hearing about from your perspective, are you happy for me to start going through those now?

If yes,

Okay great, so going back to when we worked with you previously, can you tell me more about what was happening for you at the time? [question 1]

Interview would then follow yarning style with opportunity to bring up questions at different points.

For example: I am interested in hearing more about your understanding of the program and if you were to describe this program to a family member, what would you say? [question 2]

If no.

That's completely fine, we have been through a few really important things already today. How about we organise another time for me to come back to yarn further?

# **INTERVIEW QUESTIONS**

# Addressing social and cultural needs

Can you tell me more about what was happening for [identified need eg housing] you at that time?

If you were to describe this program to a family member, what would you say?

Would you refer someone else in your family or community to this program? If yes, why?
If no, why?

# Interactions with Program Facilitator

What did you think of the role of the Facilitator?

What were the benefits you experienced from seeing the Facilitator?

# Strength-based practice

How did the program make you feel?

- Did working with the Facilitator make you feel more or less supported? In what ways?
- Did working with the Facilitator make you feel more capable? In what ways?
- Did working with the Facilitator help you to see or find any strengths you didn't know you previously had?

## Impact (Change)

What changes have you noticed since being involved in the program in yourself, or your day to day life?

Can you describe any differences in your ability to manage the challenges you face day to day, compared to before?

If you had to, would you be able to do the same thing that you did with the facilitator, by yourself?

Have you since had any experiences where you have had to seek out and engage services? How has that gone for you?

## RECRUITMENT SCRIPT

### **Text Message**

Hi [participant] - My name is [name of researcher] from Wardliparingga Aboriginal Health Equity at SAHMRI. I am getting in touch with you as you previously worked with the Cultural Pathways Program and I am hoping to chat to you more about that. I will try call you at [date/time]. Hope to chat to you soon. Thank you.

## **Phone Call 1**

Hi [participant].

My name is [name of researcher] from Wardliparingga Aboriginal Health Equity at SAHMRI. I am getting in touch with you today as you previously worked with the Cultural Pathways Program [refer to date and Facilitator] and at that time you agreed to be contacted as part of the evaluation of the program. Do you remember working with the Cultural Pathways Program?

If no,

Thank participant for their time and remind them that CPP is available for them should they require any support in the future.

If yes:

That's great, we want to yarn to participants about their experiences with the program so that we can learn from them and use what we learn to influence/improve programs for our mob.

There is no obligation to participate but if this is something you would be interested in participating in, all I need as your address or email address – whichever you prefer - to send out more information.

Once you have had time to review the information I would be back in touch to see if you would like to organise a time for us to meet at a time a location that suits you to yarn further.

Are you happy for me to send out further information?

If yes:

Obtain details for sending information.

I will send you an information sheet and a consent form – if you have any questions you can contact me otherwise I will call you in a couple days once you have had time to review information. If you would like to participate you can complete and return the form or we can schedule a time and organise to complete the consent form when we meet.

If no:

Thank participant for their time and remind them that CPP is available for them should they require any support in the future.

## If no answer

## **Text Message**

Hi [participant] sorry I missed you. Please let me know a good time to call again otherwise I will try you again in a couple of days. Thank you.

# **Phone Call 2**

Hi [participant]

I wanted to see if you had time to review the information sheet and consent form I sent you and to see if you would like to yarn more.

#### Yes

- I am really happy you are able to, did you want to send the form back or we can do it together on the day?
- Can I also confirm you are happy for me to take a look at your notes before we meet this is just to help me understand a little bit about the support you received from the program before we meet to help with our yarn?
- I can come meet with you at a time and location that suits but usually its best in a quiet place. I am happy to bring you a coffee or drink of your choice.

No

Thank participant for their time and remind them that CPP is available for them should they require any support in the future.



# INFORMATION SHEET: This Is For You to Keep

**Objectives of this research:** To evaluate the Cultural Pathways program which aims to alleviate stress and worry by increasing access to support services and improve health and wellbeing.

Who is involved: The research is being conducted by the Wardliparingga Aboriginal Health Equity Unit at the South Australian Health and Medical Research Institute (SAHMRI). Tina Brodie is the PhD candidate leading this research with supervision from Professor Alex Brown, Dr Odette Pearson and Dr Natasha Howard. This research is informed by the Addressing the Social Determinants of Health Advisory Group.

What participation will involve: Participation is entirely voluntary. If you choose not to participate this will not affect your relationship with those involved in this project or the Cultural Pathways Program. Should you be willing to participate, you will be invited to participate in the following activities:

- 1. Review of your participant record from the Cultural Pathways Program which includes the needs you identified previously, and support provided to you by the program;
- 2. An initial meeting and refresher of the Cultural Pathways Program;
- 3. Yarning (semi-structured interview) about your experiences with the Cultural Pathways Program; and
- 4. If necessary, an additional meeting to ensure you have everything you need and to connect you with any necessary services and supports.

With permission, yarning as part of the interviews will be digitally recorded and transcribed into written words to be used during analysis. If you would prefer not to be recorded, notes will be taken by the researcher during the session. If you choose to participate in an interview and subsequently wish to withdraw from the study, you may do so at any time by contacting the research team.

#### Information gathered will be used to:

inform an evaluation report which describes the experiences of Aboriginal and Torres Strait
 Islander community members in relation to their engagement with the Cultural Pathway Program;
 inform the development of a holistic service model that aims to address unmet health and social needs in the Aboriginal community to promote social and emotional wellbeing.

**Reporting of results:** The results will be reported via presentations and published reports. Reported research findings will never identify individual participants.

**Benefits to participants:** There will be no direct benefit to you as a result of participation. Findings from this study will be used to inform the development of services for Aboriginal and Torres Strait Islander community members.

**Potential risks and participant rights:** You may experience distress as a result of discussing challenging experiences. The interviewer as per the distress protocol developed for these interviews can provide immediate support and make any necessary connections to adequate support services if you become distressed. You may choose to stop yarning at any stage and withdraw your consent to participate.

**Confidentiality**: There are stringent processes in place to protect your privacy:

- Any information you provide to us will be de-identified and accessible only by the Research Team
- All quotes from participants used in reporting the results will be de-identified using broad descriptors
- All data will be stored electronically on a password protected server at the South Australian Health and Medical Research Institute in accordance with data management policies
- All data will be stored for a minimum of five years after which it will be deleted from the server including any backup copies on the server
- No third parties will be given access to the data
- The information you provide will only be used for the purposes of the study and no other, without your expressed permission

#### **Ethical Approval:**

This Research Project has been assessed and approved by the *Aboriginal Human Research Ethics Committee* of the *Aboriginal Health Council of South Australia* and the *University of Adelaide's Human Research Ethics Committee*. If you have any concerns or complaints regarding the ethical conduct of the research, please contact the Ethics Officer of the *Aboriginal Human Research Ethics Committee*, Aboriginal Health Council of South Australia: Dr Gokhan Ayturk on

**If you wish to discuss the study in more detail** please contact: Ms Tina Brodie, PhD Candidate, Wardliparingga Aboriginal Health Equity Unit, SAHMRI, on



## **CONSENT FORM**

## **Project Title:** Cultural Pathways Program Evaluation

## Participation is voluntary, this means you can say NO.

- I have received written information about this research project and the study has also been explained to me.
- I fully understand the purpose of the research and my involvement in it. I have had a chance to ask questions and am comfortable with the answers I have been given.
- I understand that I may not directly benefit from taking part in the project.
- I understand that my case records held by the Cultural Pathways Program will be reviewed prior to this interview.
- I understand that this Interview will be digitally recorded with my permission and that the researcher will turn off the tape if I ask them to.
- I understand that if I would prefer not to be recorded, written notes will be taken.
- I understand that only if I choose to participate in an interview, I will have an opportunity to review and edit my comments (which have been transcribed from the audio file into a written document) prior to the researchers' analysis.
- I understand that I may withdraw from the research project at any stage without negative impact from the Cultural Pathways Program.
- If I withdraw from the study, information I have given during an interview will be removed up until the point of analysis.
- I understand that I will retain ownership of all information (intellectual property) that I provide to the study.
- I understand that while information gained during the study may be published, I will not be identified in any way and my personal information will remain confidential.

| Name of participant:                               |                                |                              |
|--|--------------------------------|------------------------------|
| Signed:  | Date:                          |                              |
| I have explained the research project is involved. | to the participant and believe | that he/she understands what |
| Researcher's name:                                 |                                |                              |
| Researcher's signature and date:                   |                                |                              |

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