Effectiveness, cost effectiveness, acceptability and implementation barriers/facilitators of chronic kidney disease management programs for Indigenous people in Australia, New Zealand and Canada: a systematic review of mixed evidence

A thesis submitted by

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Submitted in partial fulfillment of the requirements for the Degree of

Master of Clinical Science (MClinSc).

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October 2016

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Abstract

Background: Indigenous peoples in Australia, New Zealand and Canada carry a greater burden of chronic kidney disease (CKD) than the general populations in each country, and this burden is predicted to increase. Given the human and economic cost of dialysis, understanding how to better manage CKD at earlier stages of disease progression is an important priority for practitioners and policy-makers.

Objective: To examine the evidence relating to the effectiveness, cost-effectiveness and acceptability, as well as barriers and facilitators of implementation of chronic kidney disease management programs designed for Indigenous people in Australia, Canada and New Zealand.

Inclusion criteria:

Types of participants: Indigenous people in Australia, Canada and New Zealand diagnosed with chronic kidney disease.

Types of intervention(s)/phenomena of interest: Health sector-led management programs explicitly designed to manage, slow progression or otherwise improve the lives of Indigenous people with chronic kidney disease in outpatient/community settings were considered, excluding dialysis or other forms of renal replacement therapy. Qualitative phenomena of interest were healthcare worker or patient experiences of relevant programs.

Types of studies: A broad range of study-types were considered for inclusion, including quantitative studies of effectiveness, cost and cost-effectiveness, and all types of qualitative study designs.

Types of outcomes: Outcomes of interest were indicators of clinical effectiveness, ability to self-manage, quality of life, cost and cost-benefit, acceptability, and barriers and enablers of implementation.

Search strategy: A four-step search strategy was employed to identify relevant studies published between 2000 and 2014.

Methodological quality: The studies were critically appraised using the standardized critical appraisal instruments from the Joanna Briggs Institute.

Data collection and synthesis: Quantitative and qualitative data addressing the research questions were extracted using standardised tools. Due to the heterogeneity of the included studies, quantitative data on effectiveness and cost-effectiveness were summarised in narrative and tabular form. Qualitative data was synthesized using the Joanna Briggs Institute meta-aggregation approach.

Results: Ten studies were included. Six studies provided evidence of clinical effectiveness relevant programs, two provided evidence of cost and cost-effectiveness, two provided qualitative evidence of barriers and facilitators of implementation of effective programs, and one provided quantitative evidence on the acceptability of a community-based chronic kidney disease management program.

Conclusions: The quantitative, economic and qualitative evidence in this review indicates that CKD programs tailored for Indigenous people may be effective and cost-effective, and has identified a number of facilitators to the implementation of effective and acceptable CKD management programs. Given the human cost of dialysis and the growing population of people living with CKD, it is important that we draw lessons from the available evidence, including this and other sources in Australia and internationally, to better serve Indigenous people with programs that address the barriers to receiving high-quality care and improve quality of life.

Implication for practice: Common features of effective and acceptable programs that may be incorporated into future programs were: integration within existing, trusted primary care services, adequate funding, intensive follow-up, provision of culturally-appropriate education, governance structures supporting community ownership, robust clinical systems supporting communication and a central role for Indigenous Health Workers and nurses.

Keywords: Chronic Kidney Disease, Indigenous health, systematic review, chronic disease management

Declaration

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 prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Acknowledgements

I am extremely grateful to my supervisors Dr Judith Streak-Gomersall and Dr Micah Peters for their support and detailed feedback on this review. I thank the staff of the Joanna Briggs Institute, the Menzies School of Health Research, Baker IDI Alice Springs and the Wardliparingga Aboriginal Research Unit for their practical support. I particularly thank Dr. Katharine Evans, Mr. Steven Warren and Ms. Gillian Gorham for their assistance. Special thanks also to Kurt, Eliot, Sophie and Max for their love and endurance.

Chapter 1: Background

1.1 Introduction

The systematic review of mixed evidence presented in this thesis was developed following the Joanna Briggs Institute (JBI) methodologies for reviewing quantitative, economic and qualitative evidence. The review was conducted to inform the development of effective, cost-effectiveness and acceptable chronic kidney disease (CKD) management programs for Aboriginal and Torres Strait Islander Australians (hereafter: Indigenous Australians). The questions it addresses, about the effectiveness cost-effectiveness, acceptability and barriers/facilitators to implementation of CKD programs for Indigenous Australians, were developed in response to concerns raised by practitioners working in primary health care in central Australia who saw a need for evidence to inform policy and practice in the development of CKD programs for Indigenous Australians.

Chapter 1 provides the background and rationale of the review, alongside a discussion of the role of systematic review in evidence-based healthcare. In section 1.2 an account of CKD amongst Indigenous Australians is provided. In section 1.3, systematic review methods are outlined and discussed in the context of evidence-based healthcare. In section 1.4, important considerations for systematic reviews of studies Indigenous Australians are described. In section 1.5, the objectives and questions of the review are presented.

A brief note on terminology:

There are more than 300 Indigenous Australian language groups. As such, the terms 'Aboriginal' and 'Torres Strait Islander' refer to a diverse range of people and cultural groups. There are more specific terms preferred by Aboriginal and Torres Strait Islander people living in various regions in Australia. For example, Koori, meaning 'our people,' is the preferred term for many Aboriginal people in South Eastern Australia, while 'Nunga' is the term commonly used in South Australia. The term 'Indigenous' is commonly used in international settings. While I acknowledge that this term is not preferred by all people to whom it could apply, for ease and in line with the international perspective taken in this review, the term 'Indigenous people' is used to refer to Aboriginal and Torres Strait Islander Peoples, and other Indigenous groups with similar colonial histories, namely Canadian First Nations, Metis and Inuit, and New Zealand Maori, who are the populations of interest in this review. While Native peoples living in the United States share a similar history of colonisation and also suffer disproportionately from chronic illness, differences in the health system there mean that public health and health service interventions may not be easily comparable.

1.2 Context and Relevance

1.2.1 The chronic kidney disease crisis affecting Indigenous Australians

Chronic kidney disease and associated chronic illnesses, including heart disease, stroke and diabetes, contribute half of the gap in life expectancy between Indigenous and non-Indigenous Australians.(1) Chronic kidney disease (CKD) refers to all kidney conditions that result in reduced kidney function and/or kidney damage for more than three months, regardless of underlying cause. Current guidelines recommend that diagnosis of CKD be based on five stages of kidney function in combination with three stages of kidney damage, as indicated by albuminuria (protein in the urine).(2) For reference, a more detailed description of the diagnostic criteria is provided in Appendix I. Most commonly, CKD is diagnosed in primary health care, when it has reached stage 3 or 4, as CKD is often asymptomatic in its early stages.(2, 3) Stage 5 CKD is also known as End-Stage Kidney Disease (ESKD).

Chronic kidney disease occurs more frequently and in younger age groups amongst Indigenous Australians, with rates 3–5 times the national average in urban areas and up to 30 times the national average in remote areas.(1) Mortality rates amongst Indigenous Australians are correspondingly high. Reports from Queensland, South Australia, Western Australia and the Northern Territory list CKD as a primary or associated cause of death in 16% of Aboriginal and Torres Strait Islander deaths, a rate at least 3.5 times higher than the national average.(4) Similarly, a disproportionately high burden of CKD has been found among First Nations people in Canada (5, 6) and New Zealand Maori.(7) The most common underlying cause of kidney damage in Indigenous populations is diabetic nephropathy.(3, 7, 8)

The scale of the social and economic cost of the progression of CKD to ESKD in Indigenous Australians is reflected in incidence rates of treated ESKD over six times higher than the rate among non-Indigenous Australians, as shown in Figure 1 (9). Indigenous people are hospitalized for regular dialysis 11 times the rate recorded for non-Indigenous Australians, reflecting both the higher incidence of ESKD, and a greater likelihood for Indigenous Australians to be treated with in-centre haemodialysis rather than other forms of renal replacement therapy including transplant and peritoneal dialysis, which may occur at home.(9, 10) Overall, regular dialysis accounts for more than 40% of hospitalisation episodes for Indigenous Australians.(10) Further, the incidence of ESKD in Indigenous Australians more than doubled between 1991 and 2008 and is projected to increase by 130% from 2009 to 2020.(9) Dialysis is expensive, invasive and leads to decreased quality of life, particularly for Indigenous people living in rural and remote locations, who often have to leave their homes for extended periods and/or travel long distances to access treatment.(10-12)

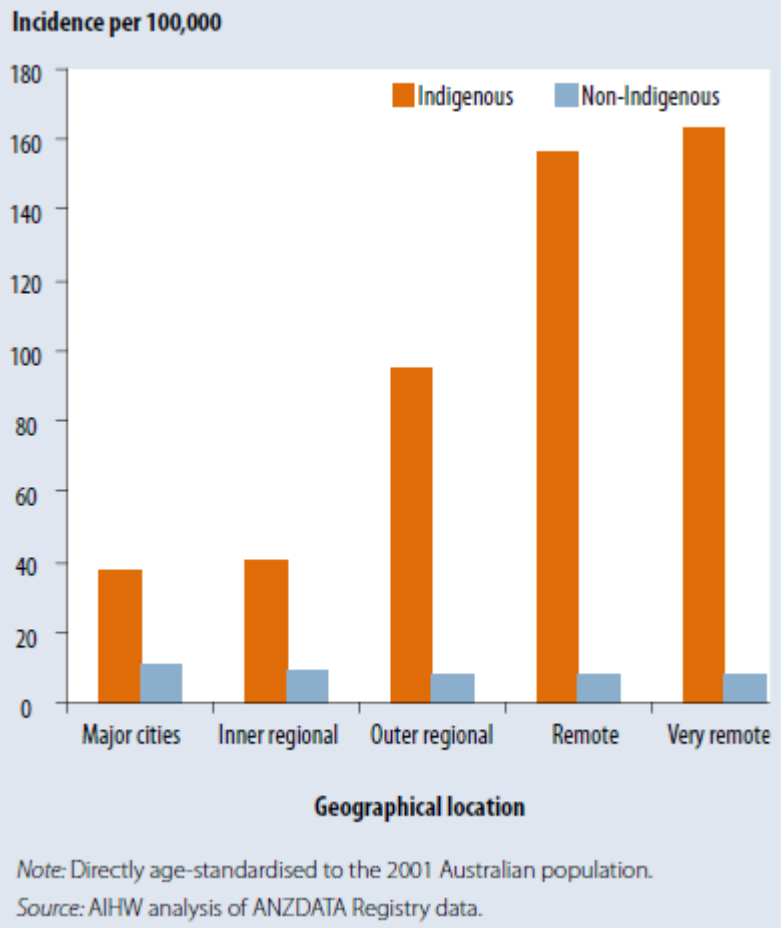

Figure 1: Incidence of treated ESKD, by Indigenous status, and geographical location, 2005-2008

High rates of clinical and environmental risk factors, including low birth weight, high blood pressure, obesity, smoking, poor nutrition and socioeconomic disadvantage, contribute to the higher burden of CKD in Indigenous populations.(9) At present, limited access to appropriate health care in many communities and poor uptake of adult health checks, which partially screen for CKD, present barriers to Indigenous Australians accessing timely and appropriate health care for CKD.(13) While acknowledging the fundamental importance of primary prevention and population-based screening as priorities for Indigenous populations and mainstream populations alike, this review focuses on identifying and synthesizing the evidence on programs and models of care for Indigenous people who have established CKD (Figure 2). The goals of management of CKD include the reduction of cardiovascular

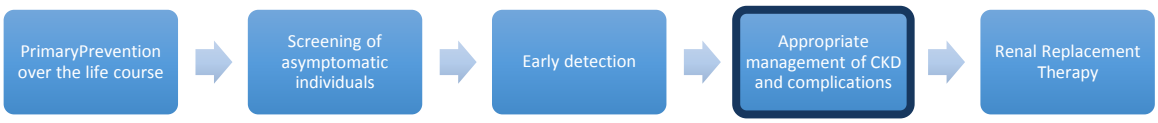

Figure 2: Focus of this review in relation to the prevention and management pathway for CKD

risk in particular by reducing blood pressure to target levels, early detection and appropriate management of complications, avoidance of nephrotoxic medications, timely referral to a nephrologist, health education and support for diet and other lifestyle changes.(14) A recent quantitative systematic review comparing standard medical care to multidisciplinary care for people in the pre-dialysis stages of CKD, examined evidence from four studies conducted in the United Kingdom, United States and Canada. Outcomes of interest were: systolic and diastolic blood pressure; estimated glomerular filtration rate (eGFR); time to renal replacement therapy; and metabolic/anaemia control. As shown in Table 1, findings were mixed but overall the reviewers concluded that care provided by a multidisciplinary team, compared to standard medical care, is effective at delaying the progression of CKD for adults in the pre-dialysis phase of the condition.(15) Education was the primary preventative strategy for three of the four multidisciplinary care programs.

Table 1: Characteristics of Studies Included in Strand and Parker, 2012 (15, p.56)

Study	Study Type	Setting	Population	Intervention	Outcomes	Result
Harris et al. 1998, USA	RCT, study length 5 yrs	CKD clinic MDC	CKD 3-5 N=437	Education	CrCL, health service use, 5-yr mortality	Increase in health in use of health services in intervention group
Devins et al. 2003, Canada	RCT, study length: 4 yrs	Hospital-based renal clinic	CKD 4-5 N=297	Psycho-educational intervention	Serum creatinine Time to RRT Self-rated health	Time to RRT significantly improved in intervention group: (x^2=14.2, p<0.00001) Increased knowledge in intervention group correlated with delay in RRT, r=0.17, p=0.03
Thanama-yooran et al. 2005, Canada	Observational study, prospective review, length: 4 yrs	CKD clinic MDC care	CKD 3-5, n=340	Education	Blood pressure, metabolic/ anaemia control	Improved metabolic control; 20% of participants had reached targets for BP control
Richards et al., 2008, UK	Observational study, length: 1 yr	GP and community based MDC team	CKD 4-5, n=483	Disease management protocol, phone follow-up and support	eGFR, BP, lipid control	Decrease in BP at 9 month follow-up compared with baseline. Systolic p<0.05, Diastolic p<0.01. Increase in eGFR and delay in CKD progression. Total and LDL cholesterol improved (p<0.01)

While healthcare programs that are effective in non-Indigenous populations may be effective and acceptable for Indigenous populations, this cannot be assumed. 'Acceptability' refers to how well the program matches the needs and context (environmental, cultural, social, psychological, physical or economic) of participants. A lack of adequate fit between the healthcare program and the social environment in which it is being implemented can render interventions ineffective, or at worst, harmful. Some interventions designed for mainstream populations may be culturally or socially inappropriate due to different understandings of health and wellbeing, and different social and cultural contexts of Indigenous peoples.' For example, the application of self-management approaches to socially disadvantaged populations has been criticized on the basis that they do not take account of the everyday challenges faced by these population groups.(16, 17) From a cultural perspective, the individualism of western self-management frameworks sit uncomfortably with the more relational social and cultural context of Indigenous peoples.(18) Further, the ability to access, understand and utilize health information, also known as health literacy, is known to be lower in culturally and linguistically diverse and disadvantaged populations.(19)

Health literacy is affected by many factors, including language barriers, low educational attainment levels, lack of familiarity with medical terminology and differing styles of learning. Also, research has identified that how and where communication occurs affects how information is received and internalized, with health consumers clearly preferring settings and communication styles that align with their world-view.(19) Qualitative research with Indigenous patients on dialysis in central and northern Australia has indicated widespread misunderstanding of the causes of kidney disease.(11) According to these studies, the problem of misunderstanding is exacerbated by pervasive miscommunication between medical staff and patients, leading to potentially distressing and dangerous consequences given the potential for misuse of medications and adverse health outcomes when treatments are not well understood.(20, 21) Other documented barriers to adherence to medical regimens include the cost of medications(22), cultural insensitivity or racism experienced at health services(23), a lack of accommodation of Indigenous cultural practices(24), complexity of prescribed treatments(25) and a family or cultural obligations precluding people from meeting the stringent requirements of treatment regimes.(21, 26, 27)

In regards to cost-effectiveness, a recent study using Markov modelling assessed cost-effectiveness of 1) intensive management versus usual care for patients with sub-optimally managed diabetes and hypertension; and 2) screening for and intensive treatment of diabetes, hypertension, and proteinuria versus usual care in the general Australian population. This study, based on meta-analyses and randomised controlled trial data, found that primary care-based screening for proteinuria, followed by treatment with angiotensin converting enzymes (ACE) inhibitors leads to improved health

outcomes and is also is also good value for money.(28) Another major study, the Central Australia Renal Study undertook economic analyses of care provided to Aboriginal people in that region and concluded that due to the high cost of RRT, the best value for money would be achieved in a scenario where investment in prevention where resulted in a 20% reduction in the projected rise of ESKD by 2020.(29, 30) One of the key recommendations from this study was to establish a model of service delivery that strengthens links between primary community-based care and tertiary care, with an additional focus on prevention across the life-course. As shown in the schematic below (Figure 3), this includes primary, secondary and tertiary prevention of kidney disease.(31)

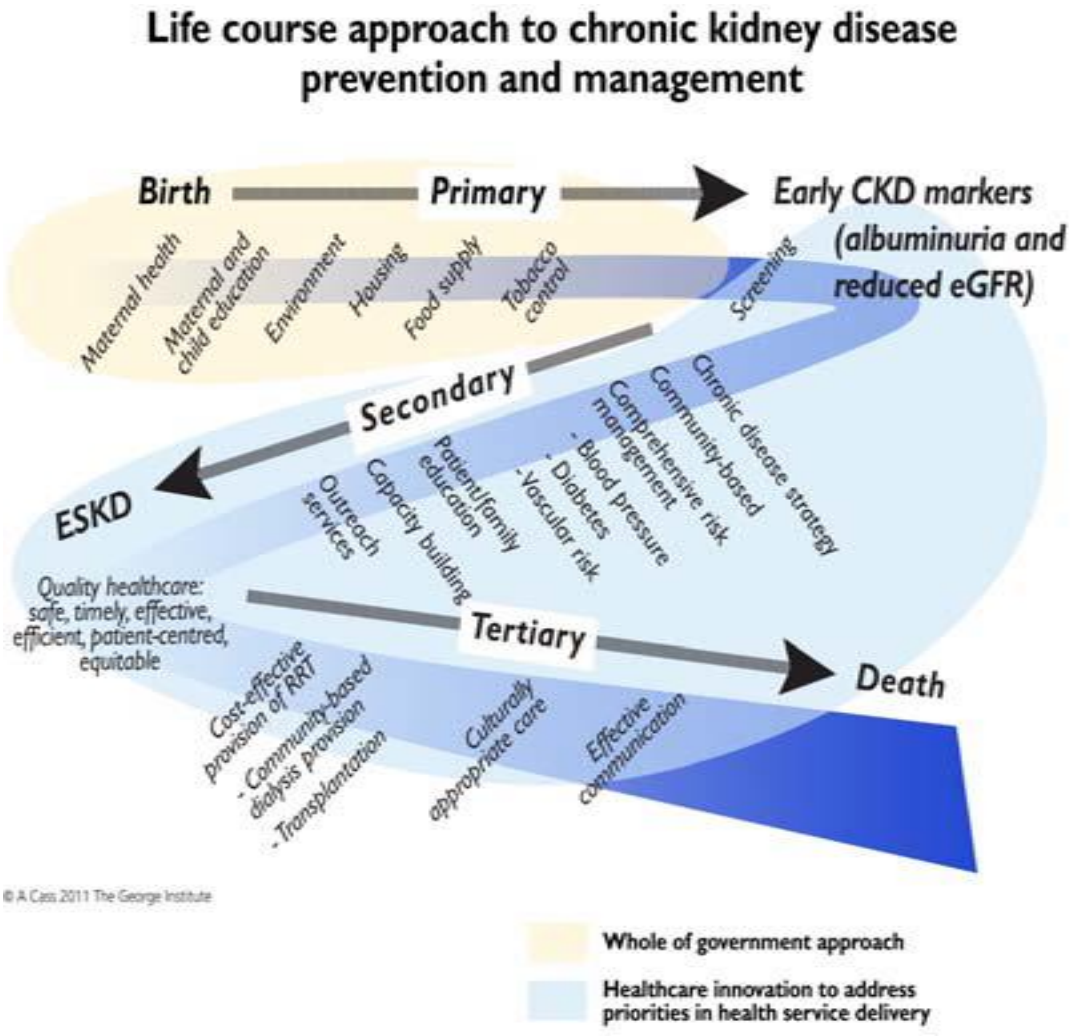

Figure 3: Schematic showing prevention activities across the life-course, taken from the Central Australian Renal Study – Technical Report, (32, p.20)

This systematic review seeks to address the gap in knowledge about how a health services may best meet the profound challenge of providing effective CKD management in Indigenous community settings. The three questions were developed with a view to providing addressing the concerns of service providers and policy makers in regards to what works (effectiveness), what it costs (economic evidence) and how it may be implemented (acceptability, barrier and facilitators to implementation). Outcomes of interest for the effectiveness questions were selected on the basis of previous studies and the known indicators of CKD progression outlined in guidelines.(2, 15) A preliminary search of the Joanna Briggs Database of Systematic Reviews and Implementation Reports, the Cochrane Database of Systematic Reviews, CINAHL, PubMed and PROSPERO revealed that there is not currently a systematic review on this topic, either published or underway.

1.2.3 The review as a response to decision makers' needs for information to guide policy and practice

A need to examine the evidence relating to CKD in the pre-dialysis stages of the condition was initially identified by service providers working with Indigenous Australians in central Australia, whose experience was that once CKD was identified, they had little to offer in the way of programs to prevent or slow the progression of CKD. This led to the disheartening perception that dialysis was inevitable, and with dialysis numbers steadily increasing(3), they felt a strong need to focus on understanding how this relentless increase may be stopped. Hence a need to examine the evidence relating to this specific part of the treatment continuum. On that basis the author (RR) proposed that a systematic review be carried out with the Joanna Briggs Institute as part of the Masters of Clinical Science program.

Coincidently, in early 2014, the Commonwealth Department of Health engaged the Menzies School of Health Research to undertake a systematic review of national and international published and grey literature to assess the available evidence relating to chronic kidney disease programs for Indigenous people. Fortunately, due to the existing relationship between the Wardliparingga Aboriginal Research Unit and the Menzies School of Health Research, researchers at Menzies were alerted to the systematic review protocol already under development, and asked to collaborate. Consequently, systematic review questions and the mixed-method design for this Master of Clinical Science thesis were adjusted and refined in consultation with the researchers working on this broader project, in order to address some of the information needs of the Australian Government. Katharine Evans from the Menzies School of Health Research acted as secondary reviewer. The review has been submitted as part of a larger report to the Australian Government, and has been published in a peer-reviewed journal.(33)

1.3 Evidence-Based Healthcare and Systematic Review

Sections 1.3 is intended to provide a general overview and discussion of how systematic review has developed with the broader movement of evidence-based healthcare.

1.3.1 Evidence-Based Medicine and Evidence-based Healthcare

In 1992, the 'Evidence-based Medicine Working Group' announced a paradigm-shift, away from clinical decision making relying on 'intuition, unsystematic clinical experience, and pathophysiologic rationale' and towards decision making grounded firmly in the examination of evidence from clinical research.(34) The emergence of this 'new paradigm,' coincided with the increasing use and acceptance of the randomized-controlled trial (RCT) as the 'gold standard' of establishing the effectiveness of interventions (drug treatments in particular); and of meta-analysis as a method of summarizing the results of a number of RCTs.(35)

Following the popularity of the EBM movement, the value of the systematic review for synthesising large quantities of research findings into a single document, has been widely accepted.(36, 37) In particular, by pooling results a systematic review has the capacity to reduce the problem of bias inherent in small studies. Transparent reporting of review processes allows readers to appraise how the review was conducted and as such, systematic review is widely perceived as more rigorous and therefore more trustworthy than narrative or other non-systematic literature review.(37) Systematic reviews of effectiveness involving transparent reporting, critical appraisal of studies and formal synthesis have been placed at the top of the EBM evidence hierarchy(38), commonly depicted as a pyramid (Figure 4)

Figure 4: Evidence hierarchy for studies addressing questions of effectiveness (39)

Since its confident beginnings in the early 1990s, the EBM movement has been criticised on a number of fronts. These criticisms reflect a concern that the enthusiasm for EBM has led to a movement away from valuing clinical experience and scientific reasoning *with* research evidence as the basis for clinical judgement, towards an uncritical over-reliance on algorithms and guidelines derived from randomised controlled trials.(40, 41) For example, it has been suggested that RCTs are limited in their applicability to clinical practice because benefits that are statistically significant in a research trial may be marginal for an individual in a clinical setting.(40) Also, the laboratory conditions required to conduct an RCT may not reflect the reality of clinical practice, where patients live in a variety of contexts, have differing values and expectations and suffer a number of comorbid medical conditions as they age.(40, 42) Further, some have argued that vested interests of pharmaceutical companies have influenced the research agenda, in some cases even having a role in defining what counts as a 'disease' in need of treatment (for example, male baldness); as well as the combination of tests and treatments that will be compared in clinical trials.(35, 40)

A more balanced and now widely-held view suggests that achieving optimal patient-centred care requires not only that EBM does not replace other sources of knowledge, but that it can incorporate relevant evidence from diverse sources.(43) Ideally EBM operates with shared decision-making, which places value on the perspective and ability of the patient to make decisions about their own health.(40) Applying EBM appropriately in clinical settings requires that practitioners take into account both the limitations of EBM (and therefore systematic reviews) alongside the values and circumstances of the patient.(40, 44) For example, some experts advocate for clinical guidelines that incorporate specific guidance about how to talk to patients about their preferences, and to communicate evidence in ways that enable patients to make appropriately informed decisions.(44)

In line with this broader view of EBM, the Joanna Briggs Institute (JBI) defines Evidence-Based Healthcare (EBHC) as the combination of evidence, context, client preference and clinical judgement.(45) 'Evidence' relates not only to effectiveness, but also the feasibility, appropriateness and meaningfulness of healthcare practices. The JBI Model of Evidence-Based Healthcare comprises five components: 1) Healthcare evidence generation; 2) Evidence synthesis; 3) Evidence transfer; and 4) Evidence implementation. Global Health is depicted as the endpoint, and the starting point, of this process (Figure 5).(46) Thus, systematic reviews of evidence, such as the one presented in this dissertation, are embedded in a research translation cycle and are designed to complement other forms of evidence, for the purpose of translating to practice and contributing to global health.

Figure 5: The JBI model of Evidence-Based Healthcare(46)

As the methods for identifying, appraising and synthesising evidence from studies with experimental designs have advanced, a growing interest in evidence synthesis across public health and social science disciplines has led to the development of methodologies for synthesising a broad range of evidence types, including qualitative data, text and opinion.(47, 48) Such methodologies broaden the range of questions that can be addressed by systematic review. Furthermore, alongside reviews of effectiveness based on quantitative research, reviews of qualitative evidence can provide important information about the human experience of a treatment or intervention, and insight into how and why an intervention does or does not work.(48, 49) Economic evidence allows consideration of trade-offs between outcomes and costs, and informed policy decisions will be made with at least evidence of both effectiveness and costs together.(50)

Further, some argue that reviews considering only one aspect of the relevant evidence, such as effectiveness (i.e. whether it works), without considering costs or other contextual factors, such as qualitative evidence for example, may lead to inefficient and wasteful policy and practice.(50) For example, Pearson et al.(49) argue that a review focusing on a single form of evidence, 'presents only half the picture and will thus have limited applicability in many contexts' (p.6). Mixed-methods synthesis offers a way of combining different types of evidence into a coherent whole to address a focused question or set of questions.(49) Such methods do not rely on the primary research studies themselves using mixed-methods (although this is also possible), but provides a process whereby syntheses of two or more types of data are conducted then aggregated; or whereby different types of data are combined in a single primary synthesis.(47)

1.4 Overview of the Steps of a Systematic Review

While the JBI approach to systematic review dominates this discussion, the JBI approach is one of many, and shares much in common with other internationally recognised approaches.(51) The approach is in line with the guidelines in the 'PRISMA Statement for Reporting Systematic Reviews of Studies that Evaluate Healthcare Interventions.'(52) As a general rule, a systematic review aims to provide a comprehensive and unbiased synthesis of all studies relevant to a particular question, or set of questions, in a single document. The internationally accepted features that define systematic review and its conduct, as outlined Aromataris et al.(36) are:

1. Protocol development: defining the objectives and inclusion criteria, and protocol publication
2. A comprehensive search to identify all relevant studies, both published and unpublished;
3. Study selection and critical appraisal of the quality of included studies, and reporting of any exclusions based on quality;
4. Data Extraction and Synthesis
5. Transparent reporting of the methodology and methods used to conduct the review.

The essential steps in conducting systematic reviews of quantitative (including economic) and qualitative evidence are outlined in more detail below, with particular reference to reviews of complex interventions and mixed evidence.

1.4.1 Developing the protocol

The questions in a systematic review aim to be clear, in order to provide meaningful information that can be used to guide decision-making.(53) A public health, interventions are often multifaceted, the questions for reviews of public health interventions are also often multifaceted and broad.(53)

Decisions about how broad or specific questions relation to public health interventions should be rests on the needs of stakeholders, the policy environment, the nature of the evidence and the time and resources available to conduct the review.

The mnemonic PICOS (Population, Intervention, Comparisons, Outcomes, Study design), or some variation, is commonly applied when developing clear and meaningful systematic review questions and inclusion criteria. As outlined by Liberati et al.(52) and described in the Joanna Briggs Institute Reviewers' Manual(47), the PICOS (or PICO) model for quantitative reviews is constructed according to:

(P) the most important characteristics of the Population;

(I) the Intervention of interest;

(C) the Comparator;

(O) the Outcome or endpoint of interest; and

(S) the Study design(s) of interest.

For qualitative reviews, the mnemonic PICo (Population, phenomena of Interest and Context) serves a similar purpose but refers to features relevant to qualitative research:

(P) What are the most important features of the Population?

(I) What is the phenomenon of Interest?

(Co) Context within which the research has taken place

Population of Interest:

In clinically-focused reviews, the population of interest is usually individuals with a specific condition, for example, 'adults diagnosed with moderate depression.' In public health reviews, the population of interest may be defined according to geographical region or membership of a particular community group, for example, 'young people transitioning to high school' or 'parents of toddler-age children living in high-rise apartments.' In qualitative reviews, issues of sampling and homogeneity may not be relevant in the same way as in quantitative reviews, but issues pertinent to qualitative experience, such as interaction with an intervention, are relevant. In all reviews, defining the key characteristics of the population of interest renders the reasons for inclusion and exclusion of studies clear and transparent.(47)

Intervention:

While clinical interventions may be easy to define, public health and health promotion interventions are often poorly described and it can take some effort to clearly specify the intervention of interest.(53) Describing the intervention, factor or exposure in detail, particularly when the intervention is multifaceted, also means defining specific terminology.(47) For example, if a workplace physical exercise intervention is the focus, reviewers need to consider whether interventions focusing on 'physical activity,' 'increased movement' or 'reduced sitting' would also be considered. In the systematic review protocol developed for this review (Appendix II), both 'programs' and 'models of care' were initially considered. However, in practice, this distinction was not found to be useful. Instead, a 'program' was defined broadly for the purpose of this review as a health sector led sequence of actions, or outline of the way a system or service will function, for the purpose of managing or preventing progression of CKD.(54)

Comparison:

The choice of comparator has implications for the interpretation of results. The comparison may be focused on one comparator, for example, surgery vs. radiotherapy for a particular type of cancer; or may be broad, for example, all alternatives, including no treatment. When the question posed in the review is broader and multiple interventions may exist (as in the present review), it may not be appropriate to limit the types of comparators considered.(47)

Outcomes of interest:

A theoretical argument for the outcomes of interest, including their scientific basis should be evident in the review.(47) Primary and secondary outcomes may be considered as long as they are measurable relevant to the review objectives. In reviews of economic evidence, outcomes are described in relation to the type of review. Therefore, outcomes may be described in relation to cost-minimisation analysis, cost-effectiveness analysis, cost-benefit analysis or cost-utility analysis. A statement about outcomes of interest is not relevant to qualitative reviews.

Study Design:

Depending on the objectives, some reviews may include a wide range of study designs, while others may include only a single study design.(52) A systematic review seeking to address a question of effectiveness of a drug, for example, may include only randomised controlled trials. Specific methods have been developed for reviewing certain types of study designs, such as prevalence studies(47), systematic reviews (umbrella reviews)(55) and the full range of economic study designs.(47, 56) Types of qualitative studies that may be considered include but are not limited to phenomenology,

grounded theory, ethnography, action research or feminist research. The decision whether to include one or more of these study types in a systematic review is made according to the research question.

Phenomena of Interest:

Qualitative reviews may be general, for example at people's general experiences of having a condition, or specific, for example examining people's experiences of a particular intervention. In either case, the phenomena of interest flow directly from the review question. For example, a review that asks, 'what are the experiences of women with endometriosis?' has as its phenomenon of interest 'experiences of having endometriosis.'(47)

Context

The context flows from the review objectives and question or questions.(47) Considerations may include cultural factors, geographic location, or details about setting. For example, the review on 'experiences of women with endometriosis,' may hypothetically consider settings such as 'South Australia,' 'or 'fertility clinics.' Context may also include consideration of cultural factors, such as prevailing health beliefs or practices, or detail about the setting such as climate or infrastructure.

1.4.2. Constructing a search strategy and searching for evidence

The search strategy is critical to achieving the objectives of the systematic review, and ideally flows from a clearly defined question and inclusion criteria. There is an art to achieving a database search that is both broad enough to capture all relevant evidence, while also being reasonably efficient.(57) As with all research methods, the search needs to be described transparently enough to be replicable. Searching is a multi-step process.(47) First, the reviewer identifies initial key words based on knowledge of the field and performs an initial search, usually using a single database, such as PubMed, to create a logic grid of key words from titles and abstracts. The logic grid is commonly designed according to the elements of the PICO, and also contains alternatives to key words, for example, 'renal' and 'kidney' would both be included in a search for studies on CKD, along with other related terms such as 'nephrology.' By analysing text words contained in the titles and abstracts of papers, and of the index terms used in a bibliographic databases, the reviewer builds a comprehensive and specific search strategy for each included database. Having performed the database-specific searches, it is common practice to review the reference lists of all studies retrieved for appraisal to search for additional studies (hand searching). A final step, also considered good practice and included in this review, is consulting experts in the field to identify any studies that may have been missed.(58)

1.4.3. Study selection and critical appraisal

Clear exclusion and inclusion criteria help to ensure the transparency and reproducibility of the process and reduces potential bias. Like the search strategy, these criteria are defined prospectively according to research question and PICO. For example, researchers seeking evidence on programs with Indigenous populations need to decide whether to include or exclude studies where Indigenous people are included as part of a larger mixed sample, or only to include studies with a sole focus on Indigenous people.(59) Study selection proceeds in two stages: first, screening the titles and abstracts of identified studies to select those that should be examined as full texts; and second, reading those that are selected for examination in detail to determine whether they meet the inclusion criteria. Study selection is followed by critical appraisal using either validated critical appraisal tools or a list of relevant criteria.(59) The current review employs the JBI approach to both study selection and critical appraisal using standardised tools.(47)

Critical appraisal is important in assessing the quality of the overall evidence base and understanding the degree of bias that may be present. Usually, studies of low quality will be excluded from the review.(60) A standardised process of critical appraisal is a key difference between a systematic and traditional literature review. There are different critical appraisal tools for different study designs spanning quantitative, qualitative, text and opinion and economic evidence (see Appendix IV). The criteria for assessment of quality vary with the type of study, for example, adequate sample size or appropriate comparators may be assessed for reviews of quantitative evidence, plausibility and comprehensiveness of costings may be assessed for reviews of economic evidence, and sufficient methodological description and supporting evidence may be assessed for reviews of qualitative evidence. In many cases studies are assigned a quality rating or score, which provides a transparent basis for comparison between studies. The results of the critical appraisal, including the criteria upon which the studies were assessed, are ideally reported in the review.

1.4.4. Data extraction and synthesis

Data is extracted that has relevance to the review question and PICO. Where relevant, outcome data is recorded as well as descriptive details such as study design, participant characteristics, methods and interventions.(61) Using standardized data extraction tools maximise reliability of the data extraction process. Meta-analysis can be used to synthesize data on treatment effects, prevalence, correlations, the accuracy of diagnostic tests, prognostic factors and economic data.(61, 62) Meta-analysis provides a measure of overall effect size, indicating the strength and direction of the

relationship between variables. Meta-analysis is not generally useful when studies are heterogeneous. That is, when they vary in design, intervention or outcomes. Heterogeneity can be measured statistically using τ2 test, a χ2 test, or an *I*2 test.(61, 63) Where meta-analysis is not possible, pooled results can be presented in narrative and tabular form.(59)

For qualitative studies, JBI uses a pragmatic, integrative (aggregative) approach.(61, 64) The meta-aggregative method aims to deliver synthesized findings that have practical use at a clinical or policy level. This is in contrast to meta-ethnography, which is more suited to generating models or higher-order explanatory theories of behaviour or experiences.(61, 65) As with other stages of data extraction and synthesis, two reviewers work independently to extract qualitative findings (themes or concepts). Findings across multiple studies are categorised according to similarity in meaning, and are then further summarized in a set of statements, referred to as synthesized findings.(61)

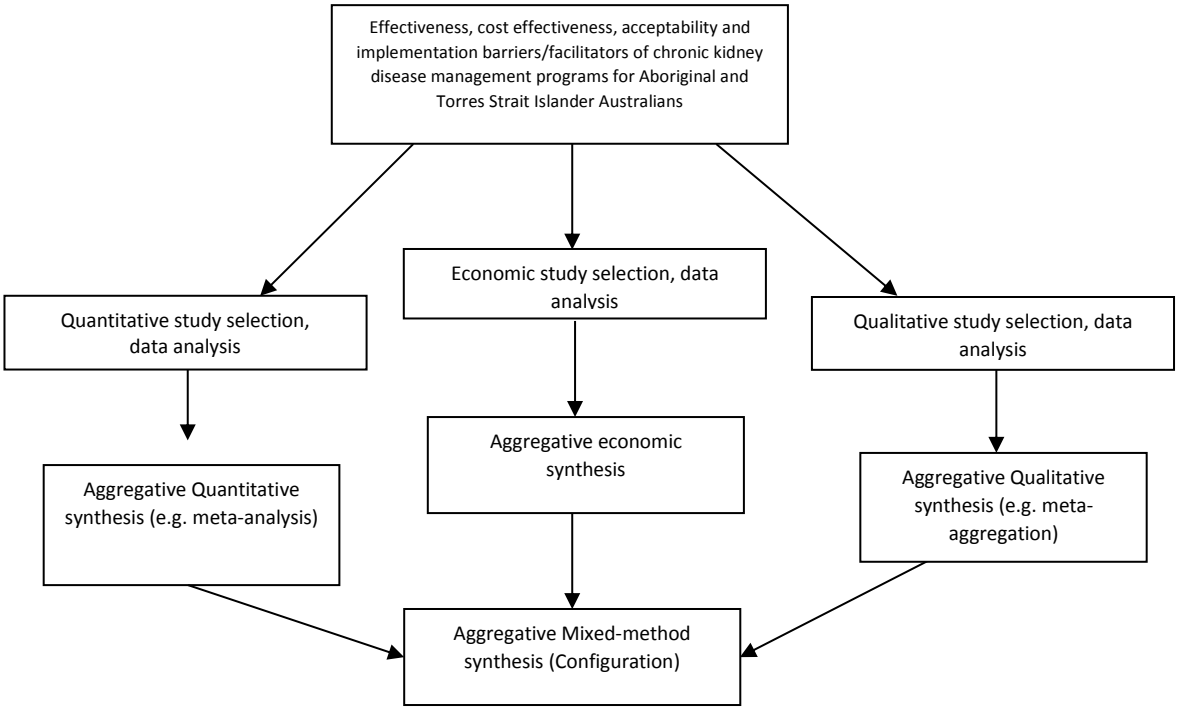

Figure 6: the JBI model of mixed method synthesis

There is debate about how data extraction and synthesis should occur in mixed-methods reviews, and there are a number of alternative approaches. For example, Realist Review uses a range of evidence types to iteratively develop theories about the relationship between context of an intervention or program, the mechanisms by which change occurs and the subsequent outcomes.(66) While acknowledging the strengths of this approach, particularly for complex interventions, it has also been criticised for a lack transparency and a lack of any explicit guidance on how to deal with contradictory

evidence. Of the available approaches, JBI has adopted a segregated approach based on the work of Sandelowski.(47, 67, 68)

Following the JBI model of mixed methods synthesis, diverse evidence types may be aggregated into a final, overall synthesis (Figure 6). This involves the configuration of the findings into a set of statements by coding quantitative data (i.e. converting quantitative findings to qualitative descriptions); attributing a thematic description to all quantitative data; assembling all of the resulting themes from quantitative and qualitative syntheses; and the configuring the themes into a set of synthesized findings in the form of a theoretical framework, set of recommendations or conclusions. It should be noted that in some cases, for example where the evidence found is too heterogeneous, it may not be possible or helpful to combine different evidence types into a single synthesis. However it may still be useful to consider independent syntheses of different evidence types because this allows decision-makers to consider a wider range of issues to inform the most efficient and effective interventions.

1.4.5 Presenting and interpreting findings

Joanna Briggs Institute endorses the PRISMA standards for presenting the findings of systematic reviews.(47, 52) The aim of reporting is in part to show, clearly and in plain language, how the interpretation of findings, along with recommendations for clinical practice and/or implications for future research stem from the data.(36) A system for grading recommendations may be used to ensure that the strength of supportive evidence is clear when using recommendations as the basis for decision making. JBI uses two grades of recommendation: Grade A is a 'strong' recommendation applied to a health management strategy when the benefits of the strategy are clear, there is clear supportive evidence, the benefits outweigh resource use and the values and preferences of the patient have been considered. Grade B is applied when the desirable effects appear to outweigh undesirable effects, but the evidence is less strong, impact on resource use may be minimal and the values and preferences of the patient or health consumer may or may not have been taken into account.(69)

1.4 Special considerations when conducting systematic reviews of evidence from research involving Indigenous Peoples

The need to use the best available evidence to inform policy and practice is as important in Indigenous health as it is in other sectors. However, systematic review has not been highly utilized to date as a tool to inform policy and practice in Indigenous Health in Australia. The underuse of systematic review stems in part from a mistrust of research in many Indigenous communities, due to

a history of research being carried out in ways that did not benefit communities, or worse, led to health policy that disempowered, marginalized and damaged already vulnerable communities.(70) As with primary research, the validity and relevance of findings is challenged when those doing the research, interpreting the findings and drawing conclusions that affect Indigenous communities, are outsiders.

In response to the risk that research poses to Indigenous peoples when carried out in ways that do not respect cultural values and ethical principles, Indigenous Australians have developed unique research values and practices. The unique obligations for Indigenous health researchers are set out in national and local guidelines for researchers.(71) These include the National Health and Medical Research Council's (NHMRC) "Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research"(72) and the South Australian Aboriginal Research Accord.(73) Similar and complementary ethical frameworks have been developed in Canada(74) and New Zealand.(75) While the same ethical standards should ideally apply to the conduct of systematic reviews of research involving Indigenous populations, there is no specific guidance for doing so.

In their overview of evidence informing chronic disease management for Indigenous Australians, Streak-Gomersall et al. (76) conclude that reviewers should be guided by community priorities to decide upon review questions, and should consult with clinicians and decision makers to ensure relevance to end-users. They also recommend the development of specific guidance and critical appraisal instruments to assist reviewers to adhere to the specific ethical and quality standards defined by Indigenous people. At the time of writing, these resources are not available, however adherence to all relevant ethical framework was considered a priority at all stages of the systematic review. Since the work was being conducted in South Australia, the South Australian Research Accord is given special consideration, and the ways in which each of the principles of the Accord have been addressed are outlined below.

PRIORITIES: Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.

Chronic kidney disease is considered a priority at the level of government policy, service provision and the Indigenous Australian community. This systematic review was carried out in response to concerns raised by practitioners in Central Australia, and subsequently the Menzies School of Health Research in Darwin and the Australian Government. Similarly, in the Next Steps Project, a recent research project carried out with the Indigenous population of South Australia to identify community priorities for research, diabetes and its complications was identified as a key priority. Particular concern was raised about young people on dialysis.(77)

INVOLVEMENT: The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.

Although the both the primary and secondary reviewers are non-Indigenous, the conduct of the review was over-seen by senior Aboriginal researchers including Professor Alex Brown, a leading Aboriginal researcher and head of Wardliparingga Aboriginal Research Unit. During the process of carrying out the review, advice was sought from Aboriginal staff in the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE) research team, on the synthesis and interpretation of findings. While there was not a formal reference group for this project, as is often recommended for Aboriginal health projects, these various individuals provided guidance that kept me, as the primary reviewer and author of this review, accountable to Aboriginal priorities.

PARTNERSHIP: Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.

This research was initiated on the basis of a relationship of trust between individuals representing Indigenous communities in south, central and northern Australia. Prior to commencing the review, I travelled to Alice Springs to consult with Aboriginal community organisations and service providers to ensure that the project was meeting the needs of those stakeholders. As a non-Indigenous researcher, an ability to work competently across cultures is necessary. After 15 years in Indigenous health research, I view this as an ongoing process of learning and development.

RESPECT: Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

The three review questions, focusing on Indigenous people and contexts, are intended to acknowledge the distinct place of Indigenous cultures and knowledge systems in Australia, New Zealand and Canada. The inclusion of a range of evidence types in the published and grey literature also acknowledges that Aboriginal knowledge is not always contained in the mainstream scientific literature. I acknowledge the limitations inherent in attempting to review evidence from diverse Indigenous populations. In Australia alone there are over 300 language groups and people living in diverse metropolitan, rural and remote locations. Care has been taken to present the review findings with this limitation in mind, and with assistance from Indigenous scholars, able to provide an Indigenous cultural 'lens' on the findings.

COMMUNICATION: Communication must be culturally and community relevant and involve a willingness to listen and learn.

In this project, two-way communication has been particularly important in the early stages of protocol development, when I was attempting to develop a systematic review protocol that addressed the concerns and priorities of health practitioners. Communicating both the value and limitations of a

systematic review was a key component of this process. Following completion of the review, findings will be communicated in a culturally relevant way, including writing a community report for a non-research audience and travelling to Alice Springs to present the findings to health practitioners.

RECIPROCITY: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

The benefit of this research as with all systematic reviews, stems from the translation of findings into practice and policy. Ultimately, this requires implementing programs that are effective, sufficiently resourced and acceptable to community, to reduce the burden of CKD in Indigenous communities.

KNOWLEDGE TRANSLATION AND EXCHANGE: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

So far, research translation has occurred in a conference presentation, a peer-reviewed journal article and an invited presentation internally at SAHMRI. Written and verbal feedback has been provided to service providers in Alice Springs, for the purpose of informing program and research development in Alice Springs, and to inform research development in that setting. The findings have been provided to the Australian Government as part of a larger report, which has not yet been released.

1.5 Review Objectives and Questions

The objectives of this systematic review were to:

1. Identify and synthesise evidence on the effectiveness of CKD programs for Indigenous peoples.

2. Identify and synthesise evidence on the costs and cost effectiveness of CKD programs for Indigenous peoples.

3. Identify and synthesise evidence on the acceptability of CKD programs to Indigenous peoples and barriers/enablers of implementation.

The review sought to address the following questions:

1. What is the effectiveness of CKD programs designed for Indigenous people in relation to outcomes, including, though not limited to: clinical indicators of CKD management including Albumin-creatinine ration, blood pressure control; the delayed progression of kidney disease/time to dialysis; and quality of life?
2. What are the costs and costs relative to benefits of CKD programs designed for Indigenous people from the perspectives of individual patients and their families, the primary health services that deliver them, tertiary health services and society as a whole?
3. What do patient and provider experiences of CKD programs designed for Indigenous people reveal about the acceptability of programs, as well as barriers and enablers to their implementation? Barriers and facilitators may be any social, economic, cultural, organisational, environmental or personal factor that inhibits or supports access and/or adherence to the health care program.

For reference, a glossary of key concepts is provided in Table 2.

Table 2: Key terms used in this systematic review

Key Concept	Definition
Albumin-Creatinine Ratio (ACR):	*Albumin is the main protein in blood plasma and creatinine is a by-product of muscle metabolism that is excreted unchanged by the kidneys. The ratio of these two in the urine is an important measure of kidney damage. The Australasian Creatinine Consensus Working Group recommend that the preferred method of ACR measurement is via a first-void spot urine specimen. Where this is not possible, a random spot urine specimen is acceptable.(78)*
Blood Pressure (BP):	*Blood pressure is a combination of: systolic blood pressure (SBP), which is the pressure in the arteries when the heart beats; and diastolic blood pressure (DBP), which is the pressure in the arteries between heartbeats. The target BP (SBP/DBP) for patients with reduced kidney function, but no albuminuria is 140/90 mmHg. If albuminuria is present, or if the patient is diabetic, consistent BP below 130/80 mmHg should be achieved.(79)*
Estimated Glomerular filtration rate (eGFR):	*eGFR is an estimate of the flow rate of filtered fluid through the kidney. The eGFR is usually calculated from serum creatinine using a prediction equation incorporating age, sex and ethnicity. The Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) formula is currently favoured, because it provides a more precise calculation.(78)*
Glycosylated haemoglobin (HbA1c):	*HbA1c is a form of haemoglobin measured to identify the average plasma glucose concentration over the past 6-8 weeks. When protein in the body reacts with glucose it becomes glycosylated and the HbA1c test reflects the average blood glucose over the lifespan of the red blood cells containing it.(80)*
Antihypertensive Medications:	*These are medications prescribed to reduce hypertension (high blood pressure) and include angiotensin II receptor blockers, calcium channel blockers and angio-converting-enzyme inhibitors (ACE inhibitors).*
Cost-effectiveness, cost-benefit and cost-utility analysis:	*These are methods commonly applied to measure and compare the resource use/costs relative to the benefits/health outcomes/impact of an intervention and comparator. Cost minimization (which assumes benefits are identical for the intervention and comparator) and cost benefit analysis are two other methods. The approaches are similar (in principle at least) with respect to how they measure cost, but differ in their conceptualisation of benefit. The cost benefit approach measures benefits in monetary units, the cost effectiveness approach in natural/clinical outcome units, and the cost utility in quality adjusted life years (QALYS) or disability adjusted life years (DALYS).*

Chapter 2: Methods of the Systematic Review

A protocol for this systematic review was developed and published in the Joanna Briggs Library of Systematic Reviews and Implementation Reports(81) (see Appendix II). The review followed best practice guidance for conducting systematic literature reviews and used the JBI method for identifying, appraising and synthesizing mixed evidence (quantitative, economic and qualitative).(47, 82)

2.1 Inclusion criteria

2.1.1 Types of participants/population

The population of interest was Indigenous people (adults 18 years or older) of Australia, Canada and New Zealand diagnosed with CKD. Studies including participants of other ethnicities (or Australian Canadian and New Zealand country populations as a whole) other ages, or with additional chronic diseases but reporting separately for participants that match the inclusion criteria were considered, as were studies where at least half (50%) of the participants were Indigenous people with CKD. In the qualitative component of the review studies including participants who were Indigenous with CKD, their Indigenous or non-Indigenous family members, significant others, carers and/or healthcare providers in Australia, New Zealand and Canada, reporting on experiences of healthcare programs matching the inclusion criteria were considered.

2.1.2 Types of intervention(s)/phenomena of interest

Studies reporting data on health sector-led management programs explicitly designed to manage, slow progression or otherwise improve the lives of people with CKD were considered for inclusion. Studies evaluating renal replacement therapy (dialysis or transplant) were excluded. With respect to comparators, in the quantitative effectiveness and economic review components, all health care program/model alternatives were considered, including comparisons with no CKD management program, usual care, non-Indigenous people or all ethnicities in Australia, New Zealand and Canada.

The qualitative component of the review considered studies that investigated healthcare worker and/or patient experiences/perceptions of delivery of CKD programs provided to participants matching the inclusion criteria, in relation to though not limited to acceptability, patient satisfaction, engagement/participation, self-management and barriers and facilitators of program implementation. The term ‘implementation’ refers to the process of putting a program into practice, for the purpose of this review, barriers and facilitators of implementation are defined broadly as factors or processes that influence program execution or participation.

2.1.3 Context

All CKD programs delivered in outpatient settings in Australia, New Zealand and Canada were considered. This includes hospital outpatient, primary healthcare and community settings and outreach services to primary health facilities by multidisciplinary and specialist services.

2.1.4 Types of outcomes

Studies were considered for inclusion if they reported on clinical end-points such as dialysis starts (also sometimes reported as 'time to dialysis' or 'kidney death') or mortality. Other indicators of clinical effectiveness were chosen on the basis of the Kidney Health Australia (KHA) guidelines for the management of CKD in general practice(83), which recommend three routine tests for the 'Kidney Health Check': urine albumin: creatinine ratio (ACR); estimated glomerular filtration rate (eGFR); and blood pressure (BP). Studies reporting substitute measures of urinary protein were considered for inclusion if ACR was not reported. Studies reporting change in glycated haemoglobin (HbA1c) were considered for inclusion because of the high prevalence of diabetic nephropathy amongst Indigenous peoples with kidney disease. Studies reporting the number of prescribed medications or adherence to medication, were also considered for inclusion.

Studies were also considered if they reported on:

- quality of life, program acceptability and satisfaction;
- psychosocial and behavioural factors including, but not limited to: ability to self-manage, adherence, depression, anxiety, self-efficacy and service utilization measured with psychometric or other survey instruments;
- barriers and facilitators to implementation; or
- costs, and/or costs relative to benefits and/or savings- associated with implementing the program/model, only implementing part of the model/program, or doing nothing (no CKD program

All measures for the range of included outcomes were considered and, where relevant, limitations of the measures used, for example where an instrument had not been validated for use with Indigenous populations, were reported.

2.1.5 Types of studies

Studies reporting on primary research were considered for inclusion. Studies considered in the component of the review addressing the question of effectiveness (Q1) were:

- Randomised controlled trials (RCTs)
- Non-randomised controlled trials
- Observational studies e.g.
    - Retrospective and prospective cohort studies
    - Case control studies
    - Health service studies
    - Health service evaluations
    - Analytic cross-sectional studies
    - Descriptive epidemiological study designs

In the component of the review addressing the questions about costs, savings and costs relative to benefits, economic evaluations and costing studies (including model-based studies):

- All costing and economic evaluation study designs were considered for inclusion.
- Studies based on empirical data only, or empirical data and modelling were considered.

In the qualitative review component, all qualitative study designs were considered, including descriptive, ethnography, phenomenology, grounded theory studies, action research and evaluations including developmental evaluation. Mixed method studies were considered for inclusion. Studies that were, solely prevalence studies or epidemiological studies showing relationships between indicators or risk factors in the absence of a specific program or model of care were not considered for inclusion.

2.2 Search strategy

The search strategy sought both published and unpublished studies written in English. The date range was restricted to publications between 2000 and 2014 because changes in medical technology, data collection in healthcare, dollar values for cost evaluations; and prevailing government strategy, policy and funding arrangements mean that earlier findings were likely to be less relevant. A four-step search strategy was used, as shown in Table 3. An initial limited search of PubMed and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was then undertaken across all included databases. The reference list of all identified reports and articles were searched for additional studies.

Table 3: Four-step search strategy

Step	Search Strategy
1	Limited search of PubMed and CINAHL, analysis of text words in titles and abstracts and of index terms used to describe t articles.
2	Search using all identified keywords and index terms across all included databases: PubMed, EBSCO CINAHL, Embase, ATSIHealth via Informit online, Web of Science, PsycInfo, APAIS Health databases, Australian Indigenous Health InfoNet and Primary Health Care Research and Information Service (PHCRIS). Grey Literature: Mednar, Trove, Google Grey, OCLC WorldCat Dissertations and Theses, Canada Theses Portal and other sources: websites of relevant organizations in each country including Kidney Health Australia, Kidney Health New Zealand and The Kidney Foundation of Canada, Australian Institute of Torres Strait Islander Studies, NativeWeb and World Health Organization.*
3	Search of reference lists of all included reports and articles for additional studies.
4	Hand searching of *Pimatisiwin: A journal of Aboriginal and Indigenous Community Hea*lth, and consultation with experts.

*Searches for each database available from the author.

The four-step search strategy is outlined in Table 3. Relevant databases and electronic sources were searched for peer-reviewed and grey literature. The complete search strategy for PubMed is included as Appendix III. This search strategy was adapted for all other databases using database-specific search strings. A simplified set of key-words was used for grey literature searching according to the requirements of each search engine. Experts in the field were contacted, including Associate Professor David Peiris, Professor Alan Cass and Professor Alex Brown (Australia); Professor Kelvin Lynn and Rachael Walker (NZ); and Associate Professor Karen Yeates (Canada), to identify additional studies.

2.3 Assessment of methodological quality

Two reviewers assessed methodological quality using relevant Joanna Briggs Institute (JBI) standardized critical appraisal instruments(47; Appendix IV). Quantitative papers examining CKD program effectiveness were assessed using the tools contained in the 'JBI Meta-Analysis of Statistics Assessment and Review Instrument' (JBI-MAStARI). JBI-MAStARI has separate tools for appraising different study designs. In the absence of a specific tool tailored for appraisal of uncontrolled before and after studies, these were appraised using the 'descriptive/case series' appraisal tool. Studies of costs and cost effectiveness were assessed using the tools contained in the 'JBI Analysis of Cost, Technology and Utilization Assessment and Review Instrument' (JBI-ACTUARI). Qualitative papers were assessed using the tool in the 'JBI Qualitative Assessment and Review Instrument' (JBI-QARI).

Any disagreements that arose between the reviewers were resolved through discussion, or by consulting a third reviewer (JSG or GG). The checklists had between nine and 11 questions, to which

there were four possible responses: 'Yes', 'No', 'Unclear' and 'Not applicable.'(47) The quality of the evidence presented in each article was classified according to the percentage of 'Yes' responses (excluding those questions judged not applicable), as described below:

- Good quality: ≥80% of answers 'Yes'
- Moderate quality: 50-80% of answers 'Yes'
- Poor quality: <50% of answers 'Yes'.

Those articles deemed poor quality were excluded.

2.4 Data Extraction and Synthesis

2.4.1 Stage 1 data extraction

Quantitative, economic and qualitative data were extracted from papers included in the review using the slightly modified data extraction tools from JBI-MAStARI, JBI-ACTUARI and JBI-QARI respectively (These are included in Appendix V). Details about study characteristics (e.g. interventions, populations, settings and study methods) were extracted, as well as findings for the outcomes/phenomena of interest relevant to the review. Authors were contacted where necessary to clarify reported data or access information not reported.

2.4.2 Data synthesis

Data from the six studies addressing question 1 on the effectiveness of CKD programs were quantitative, and were therefore pooled using JBI-MAStARI. For included studies on the effectiveness of health care programs, effect sizes expressed as odds ratio (for categorical data) and weighted mean differences (for continuous data) and their 95% confidence intervals were recorded. The findings from included quantitative studies were synthesized using narrative and tables. The heterogeneity of studies in terms of interventions, populations, reported data and study designs precluded meta-analysis. As statistical pooling was not possible the findings were presented in narrative form including tables and figures to aid in data presentation where appropriate. Quantitative evidence on barriers and facilitators was described in tabular and narrative form. Studies addressing question 2, on costs and cost-effectiveness, provided quantitative economic data and were synthesized in JBI-ACTUARI and reported in narrative and tables.

Qualitative data addressing question 3 were pooled using JBI-QARI. This involved first pooling the findings judged to be credible or unequivocal. Findings are the units of analysis identified by the

researcher and presented as themes, metaphors or concepts, ideally with some supporting evidence, such as an extract or direct quote from the raw data, or an explanation by the researcher of how that finding was drawn from the data. Findings with supporting data were considered at least credible, and findings where the link between the supporting data and the finding were absolutely clear were considered unequivocal. The second staged involved developing categories of these findings defined by similarity in their meaning. Finally, the categories were subjected to a meta-synthesis to produce a single comprehensive of synthesized finding addressing the question that could be used as a basis for evidence-based practice.(47, 61) Quantitative data addressing question 3 was presented in tabular and narrative form. Given the small number of studies and heterogeneous nature of the study designs and data reported, stage two data extraction and synthesis was deemed inappropriate. Instead, the findings of the review are presented as separate but interrelated syntheses addressing the three review questions.

Chapter 3: Results of the Systematic Review

Due to the review presenting three separate but related syntheses, the presentation of results differs slightly from that which may be expected for a single synthesis. The search, study selection, an overview of included articles and critical appraisal are presented for all three questions together. Findings, including the characteristics of included studies, data extraction and synthesis are then presented separately for each question.

For reference, the review questions were:

Question one (Q1):

> What is the effectiveness of CKD programs designed for Indigenous people in relation to outcomes, including, though not limited to: clinical indicators of CKD management such as blood pressure control; the delayed progression of kidney disease/time to dialysis; and quality of life?

Question two (Q2):

> What are the costs and costs relative to benefits of CKD programs designed for Indigenous people from the perspectives of individual patients and their families, the primary health services that deliver them, tertiary health services and society as a whole?

Question three (Q3):

> What do patient and provider experiences of CKD programs designed for Indigenous people reveal about the acceptability of programs, as well as barriers and enablers of implementation?

3.1 Search and Study Selection

As shown in Figure 7, the search returned 2246 unique citations that were screened by title and abstract against the review inclusion criteria. Checking the reference lists yielded one additional article that was included for full-text examination. Of these 137 articles, 85 were excluded on the basis of study design, 23 on the basis of population of interest, 2 were conducted in inpatient settings and 12 were duplicates (eg. where there were multiple publications from the same study). Four articles were not accessible after extensive efforts to access electronically and contacting the authors. Of the eleven remaining studies, one was later excluded on the basis of quality(84), leaving 10 included studies. Of the ten included studies, six provided quantitative evidence addressing the question of intervention effectiveness, two on costs (1) and cost effectiveness (1), two provided qualitative evidence on barriers/facilitators of CKD program implementation and one study provided

quantitative evidence on CKD program acceptability. A list of the studies excluded at full text examination with reasons for exclusion is included as Appendix VI.

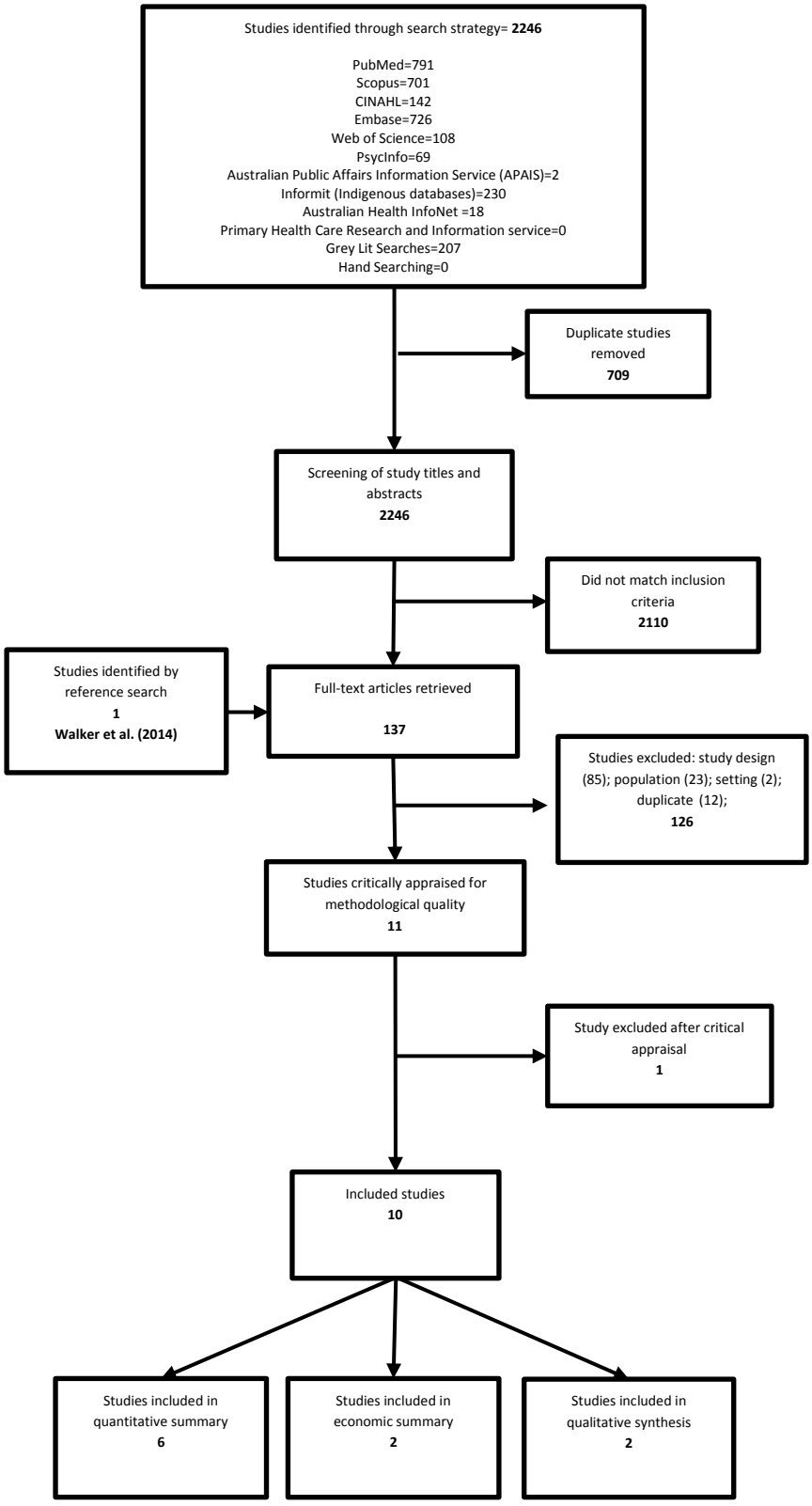

Figure 7: PRISMA flow diagram of Search and Study Selection(85)

3.2 Overview of the Included Studies

Table 4 provides an overview of the ten articles that met the review's inclusion and quality criteria, and were used to address one or more review question. Six articles reported on studies conducted in Australia and five reported on studies undertaken in NZ; none reported on studies conducted in Canada. Three of the NZ articles were the result of NZ Ministry of Health funding in 2010 for pilot studies that aimed to improve the management of CKD patients.(86-88)

While some articles reported more than one type of evidence, only one type per article matched the inclusion criteria. Six articles contributed quantitative evidence that addressed review question number one on the effectiveness of programs. Two articles reported economic evidence relevant to question two. Three articles contributed evidence relevant to question three on the acceptability and barriers/enablers to program implementation (two present qualitative interview data and one presents the results of a quantitative survey).

Pairs of studies that reported findings from the same CKD programs were: Walker et al. (87, 88); and Kondalsamy-Chennakesavan(90) and Baker et al.(91). The latter two reported on the Menzies Renal Treatment Program (MRTP). The search identified a number of articles that reported effectiveness data on the MRTP. The thesis by Kondalsamy-Chennakesavan(90) was selected because it contained the most complete account.

Table 4: Overview of studies included in the review

Article details (chronological order)	Country	Study design (evidence type)	Questions addressed
Gador-Whyte et al. (2014). 'Cost of best-practice primary care management of chronic disease in a remote Aboriginal community'. *Med J Aust* 200: 663–666.(92)	Australia	Partial economic evaluation/costing study (economic)	2
Tan et al. (2014). 'Intensification of blood pressure treatment in Pasifika people with type 2 diabetes and renal disease: a cohort study in primary care'. *NZ Med J* 127: 17–26.(86)	NZ	Prospective cohort, no control (quantitative)	1
Walker et al. (2014). 'A prospective clinical trial of specialist renal nursing in the primary care setting to prevent progression of chronic kidney: a quality improvement report'. *BMC Fam Pract* 15: 155.(88)	NZ	Prospective cohort, no control (quantitative)	1
Hotu (2013). *Optimising blood pressure control in Māori and Pacific patients with type 2 diabetes mellitus and established diabetic nephropathy in New Zealand*. PhD thesis, The University of Auckland.(93)	NZ	RCT (quantitative)	1
Walker et al. (2013). 'Improving self-management in chronic kidney disease: a pilot study'. *Ren Soc Australas J* 9: 116–125.(87)	NZ	Prospective cohort, no control (quantitative)	1
Tchan et al. (2012). *The Outback Vascular Health Service evaluation report*. Maari Ma Health Aboriginal Corporation.(94)	Australia	Descriptive program evaluation (qualitative)	3
Walker et al. (2012). 'Perceptions of key influences on effective pre-dialysis nursing care'. *Contemp Nurse* 42: 28–35.(95)	NZ	Exploratory descriptive study (qualitative)	3
Shephard et al. (2006). 'Results of an Aboriginal community-based renal disease management program incorporating point of care testing for urine albumin: creatinine ratio'. *Rur Rem Health* 6: 591.(96)	Australia	Prospective cohort, no control (quantitative)	1, 3
Baker et al. (2005). 'Cost-effectiveness analysis of a kidney and cardiovascular disease treatment program in an Australian Aboriginal population'. *Adv Chronic Kidney D* 12: 22–31.(91)	Australia	Economic evaluation (economic)	2
Kondalsamy-Chennakesavan (2003). *Sustaining renal health outcomes following community-based intervention program*. MPH thesis, Northern Territory University.(90)	Australia	Retrospective cohorts, no control (quantitative)	1

3.3 Methodological Quality of the Included Studies

The majority of studies were rated as moderate quality, two were good quality and one study of poor quality. Weaknesses identified included a lack of randomisation and insufficient follow-up period for quantitative studies, a lack of clarity around the credibility of values assigned to costs and outcomes for economic studies, and the absence of a statement about the cultural or theoretical position of the researcher for qualitative studies. Table 5 presents the results of the quality assessment. For ease, in this chapter from this point on, included studies are referred to in the text by the name of the first author and year of publication.

Studies Addressing CKD program effectiveness (Q1)

Hotu (2013) was rated as good quality. Although it was not possible for the participants and assessors of the RCT to be blinded to treatment allocation, assessment of the outcomes could have been blinded. Of the articles rated moderate quality, Tan et al. (2014) was not based on a random sample, there was no comparator group, confounding factors were not reported, patients lost to follow-up were not included in the analyses and the mean follow-up period was 21 months. Walker et al. (2014) was not based on a random sample, there was no comparator group and follow-up was 12 months. In addition to these issues, Walker et al. (2013) did not include patients lost to follow-up. Shephard et al. (2006) was not based on a random sample, there was no comparator group, confounding factors were not reported, the mean follow-up period was 15 months and outcomes were not measured reliably. The two cohorts compared in Kondalsamy-Chennakesavan (2003) differed in their clinical parameters at baseline, it was unclear if bias was minimized in relation to selection of cases and controls and the author was unable to ascertain the reliability of all outcomes. Amega (2012, 84) was a brief article with limited data and was rated poor quality. Attempts to obtain additional data from the author were unsuccessful and so this study was excluded. The implications of the quality of the studies are outlined in Chapter 4 (Discussion).

Studies Addressing CKD program costs and cost-effectiveness (Q2)

Both studies presenting economic evidence were rated as moderate quality. Gador-Whyte et al. (2014) was a partial economic evaluation that estimated the costs of a best practice program and the funding gap between the costs of best practice care and actual care. In this study, best practice was defined according to the Central Australian Rural Practitioners Association Standard Treatment Manual; CARPA STM.(97) Identification and measurement of costs and alternatives was considered comprehensive, accurate and credible, however generalizability to other settings was not clear, and there was no incremental analysis of costs and consequences, nor sensitivity analysis that would

enable comparison of alternatives. Baker et al. provide a full economic evaluation of the costs and costs relative to benefits of the CKD program. The available evidence indicated that effectiveness had been established and costs and outcomes measured accurately for this setting at this point in time, it was not clear whether all relevant costs and outcomes for each alternative were identified or valued credibly.

Studies Addressing CKD program acceptability and barriers/ facilitators of implementation (Q3)

Both of the qualitative studies outlined provider rather than patient experiences of delivering CKD care to Indigenous populations. Tchan et al. (2012) was a study of 'moderate' quality and Walker et al. (2012) was a study of 'good' quality. Tchan et al. (2012) provided limited information about the interviews, including the ethnicity of the interviewees, the identity of the interviewers, the interview settings and methods of data analysis. Walker et al. (2012) did not include either a statement locating the researcher culturally or theoretically, or address the influence of the researcher. This is particularly important in cross-cultural settings, where the cultural or theoretical background of the researcher may affect the way that questions are asked – for example, in relation to the language used, trust in the researcher or using cultural knowledge to guide questioning.

Table 5: Assessment of Methodological Quality

	RCT	Horu (2013)	Comparable Cohort	Kondalsamy-Chennakesavan (2003)	Descriptive/Case Series	Tan (2014)	Walker (2014)	Walker (2013)	Amega (2012)	Shephard (2006)	Qualitative	Walker (2012)	Tchan (2012)	Economic	Gador-Whyte (2014)	Baker (2005)
Q1.	Was the assignment to treatment groups truly random?	Y	Is the sample representative of patients in the population as a whole?	Y	Was the study based on a random or pseudo-random sample?	N	N	N	N	N	There is congruity between the stated philosophical perspective and the research methodology?	Y	U	Is there a well-defined question?	Y	Y
Q2.	Were participants blinded to treatment?	N	Are the patients at a similar point in the course of their condition?	N	Were the criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	There is congruity between the research methodology and the research question or objectives?	Y	Y	Is there a comprehensive description of alternatives?	NA	NA
Q3.	Was allocation to treatment groups concealed from the allocator?	Y	Has bias been minimized in relation to selection of cases and controls?	U	Were confounding factors identified and strategies to deal with them stated?	N	Y	Y	N	N	There is congruity between the research methodology and the methods used to collect data?	Y	Y	Are all important and relevant costs and outcomes for each alternative identified?	Y	U
Q4.	Were the outcomes of people who withdrew described and included in the analysis	Y	Are confounding factors identified and strategies to deal with them stated?	Y	Were outcomes assessed using objective criteria?	Y	Y	Y	Y	Y	There is congruity between the research methodology and the representation and analysis of data?	Y	Y	Has clinical effectiveness been established?	NA	Y
Q5	Were those assessing outcomes blind to the treatment allocation?	N	Are outcomes assessed using objective criteria?	Y	If comparisons are being made, were there sufficient descriptions of the groups?	NA	NA	NA	N	NA	There is congruence between the research methodology and the interpretation of results?	Y	Y	Are costs and outcomes measured accurately?	Y	Y
Q6.	Were the control and treatment groups comparable at entry?	Y	Was follow-up carried out over a sufficient time period?	Y	Was follow-up carried out over a sufficient time period?	N	N	N	U	N	There is a statement locating the researcher culturally or theoretically	N	N	Are costs and outcomes valued credibly?	Y	U
Q7.	Were groups treated identically other than for the named interventions?	Y	Were the outcomes of people who withdrew described and included in the analysis?	Y	Were the outcomes of people who withdrew included in the analysis?	N	Y	Y	N	Y	The influence of the researcher on the research, and vice-versa, is addressed	N	N	Are costs and outcomes adjusted for differential timing?	U	Y
Q8.	Were outcomes measured in the same way for all groups?	Y	Were outcomes measured in a reliable way?	U	Were outcomes measured in a reliable way?	Y	Y	Y	U	N	Participants and their voices are adequately represented	Y	Y	Is there an incremental analysis of costs and consequences?	N	Y
Q9.	Were outcomes measured in a reliable way?	Y	Was appropriate statistical analyses used?	Y	Was appropriate statistical analysis used?	Y	Y	Y	NA	Y	The research is ethical according to current criteria or evidence of ethical approval by an appropriate body	Y	Y	Are sensitivity analyses conducted to investigate uncertainty in estimates of cost or consequences?	N	Y
Q10.	Was appropriate statistical analysis used?	Y									Conclusions drawn in the research report appear to flow from the analysis or interpretation of the data	Y	Y	Do study results include all issues of concern to users?	Y	U
Q11.														Are the results generalizable to the setting of interest in the review?	U	U
	Quality Rating*	8/10 Good		6/9 Moderate		4/8 Moderate	6/8 Moderate	6/8 Moderate	2/8 Poor	4/8 Moderate		8/10 Good	7/10 Moderate		5/9 Moderate	6/10 Moderate

Y= yes; N=No, U=unclear. *Good: at least 80%; Moderate: 50-80%; Poor: less than 50%

3.3 Results addressing CKD program effectiveness (Q1): Study characteristics and findings

3.3.1 Characteristics of studies

As outlined in Table 6, of the six studies providing quantitative evidence on program effectiveness, four were conducted in New Zealand and two in Australia. Four of these were uncontrolled prospective cohort designs carried out over one (Walker 2013; 2014) or two years (Shephard, 2006; Tan 2014). Of a number of possible publications reporting effectiveness of the Menzies Renal Treatment Program (MRTP), the thesis by Kondalsamy-Chennakesavan (2003) was considered the most relevant and comprehensive, including two comparisons: 1) before and after the MRTP was handed over to the Tiwi Health Board (THB); and 2) outcomes from the MRTP versus the THB-run Continuing Care Trial (CCT). Australian participants were younger, on average, than the New Zealand participants (weighted averages 44.1 years and 57.8 years respectively). The 437 participants overall were split evenly between men and women (49.9% men). Please see Appendix VII for further details about the key components of each of the programs described in these studies.

Table 6: Characteristics of studies addressing the effectiveness of CKD programs (Q1)

Study	Objective	Study Design	Setting	Intervention and Comparator	Comparator	Participants	Outcomes measured
Tan et al. (2014) *Langimalie Tongan Health Centre Study*	To determine the effectiveness of a Primary Health Care (PHC) based, nurse-led CKD program with Tongan-speaking staff aiming to improve medication adherence and clinical outcomes	2-year prospective uncontrolled cohort study, conducted 2011 – 2013	NZ urban area, PHC service in Auckland with Tongan-speaking staff	**Nurse-led** with input from GP and diabetologist when necessary. Focus on **prescribing antihypertensives** and **improving adherence**. BP measured 2–6 weekly. Some **outreach** and lifestyle, dietary and self-care **education**.	No comparator.	43 Pasifika patients with type 2 diabetes, CKD (mostly stages 2 and 3) and hypertension. Mean age 53 yrs, 77% male. 39 available for follow-up at ≥17 mths.	BP, no. antihypertensives, eGFR, ACR, HbA1c
Walker et al. (2013, 2014) *Preventing Progression of Chronic Kidney Disease in Primary Care (CKD Pilot)*	To test feasibility and effectiveness of a specialist renal nurse-led self-management intervention to slow progression of CKD.	1 year prospective uncontrolled cohort study, conducted 2011–2012.	NZ, rural area; two PHC practices in Hawke's Bay.	**Specialist nurse-led** partnership with primary care clinicians. Focus on **coaching to improve self-management**. Individual **educational and clinical care plans** developed followed by 12 weeks of fortnightly self-management sessions, with monitoring to 12 months. Some **outreach** and **free care, medications and transport**.	No comparator.	52 patients (37 NZ Māori, 10 Cook Island Māori/Samoan and 5 NZ European) with type 2 diabetes, CKD	BP, no. antihypertensives, eGFR, ACR, HbA1c, self-management.
Hotu (2013) *DElay Future End-Stage Nephropathy due to Diabetes' (DEFEND)*	To determine whether a nurse-led community-based CKD program involving a Māori or Pasifika health care assistant (HCA) ('community care'; CC) is more clinically effective than 'usual care' (UC).	1 year RCT, conducted 2004–2006.	NZ, urban area; hospital clinics and PHC services in Auckland.	**Nurse-led** with focus on **prescribing antihypertensives** and **improving adherence**. **Monthly outreach** by HCA to monitor BP, promote adherence and provide **free transport**. Lifestyle, dietary and self-care **education**. Received routine care as necessary.	Lifestyle, dietary and self-care education. Usual care by GP and renal clinic.	65 Māori and Pasifika patients with type 2 diabetes, CKD (mostly stage 3) and hypertension (CC: n=33; UC: n=32). Mean age: CC: 63; UC: 60 years; % male: CC: 55%; UC: 53%. 58 available for follow-up at 12 months (CC: n=30; UC: n=28).	BP, no. antihypertensives, adherence, eGFR, ACR, HbA1c.
Shephard et al. (2006) *Umoona Kidney Project*	To determine the clinical effectiveness (and acceptability- see below) of the Umoona Kidney Project, a PHC-based partnership between the local Aboriginal community controlled health service (ACCHS) and visiting specialists from Adelaide.	2 year prospective uncontrolled cohort study, conducted 1998–2000.	Australia, remote area; ACCHS in Coober Pedy.	**Specialist-run** with focus on **prescribing antihypertensives**, delivering ACR **point of care tests** (POCT) and **ascertaining acceptability** of project. **Regular visits by nephrologists** and 6-monthly monitoring of clinical parameters. Lifestyle and dietary **education** provided. Some **outreach**.	No comparator.	35 Aboriginal patients with hypertension and with or at risk of CKD (20 had albuminuria). Mean age 49 years, 54% male. Patients followed for a mean of 15 months with none lost to follow-up.	BP, no. antihypertensives, adherence, eGFR, ACR, program acceptability.
Kondalsamy-Chennakesavan (2003) *Menzies Renal Treatment Program (MRTP) Continuing Care Trial (CCT)*	1) To determine whether improvements in BP and metabolic control were sustained following the handover of the visiting specialist-run MRTP to the local THB. 2) To compare the effectiveness of the pre-handover MRTP to the concurrently run THB-managed CCT.	2.5 and 5.5 year retrospective uncontrolled cohort study, comparing cohorts: 1) 66 month MRTP cohort (n=101) comparing pre-handover (1995–1999) and post-handover (2000-2001). 2) 30 month MRTP (n=149) and CCT (n=89) cohorts comparing pre-handover MRTP to CCT (1997–2000).	Australia, remote area; ACCHS on the Tiwi Islands, 80 km north of Darwin.	The MRTP was a **specialist-run** project that ran alongside the local health care facilities. The focus was **prescribing antihypertensives**. Lifestyle and dietary **education** delivered and individual **treatment plans developed**. **Systematic recalls** and **active follow-up** to monitor BP.	CCT patients assigned a chronic disease **care plan** and were managed in **routine PHC** setting. No specific resources for renal patients, **opportunistic follow-up**, less systematic medical oversight.	238 Aboriginal patients with hypertension and/or CKD (mostly stages 1 and 2). Mean age: MRTP: 44; CCT: 42 years; % male: MRTP: 45%; CCT: 44%.	BP, HbA1c.

3.3.2 Findings on the effectiveness of CKD programs (Q1)

Data on eight outcomes were extracted. These were: ACR; eGFR; BP; number of antihypertensive medications; medication adherence; HbA1c; and self-management. No studies reported data on hard end-points such as dialysis or death. There were also no data reported on quality of life or other psychosocial variables, such as depression or stress (see Table 7). All six programs reported BP data, with three also reporting the proportion of patients with appropriate BP control (Tan et al., 2014, Kondalsamy-Chennakesavan, 2003).

All intervention groups showed significant reductions in systolic blood pressure from baseline or in relation to comparator groups. Systolic blood pressure is reported in the summary data in Table 7 as this is the more reliable indicator of CKD.(97, 98) Where it was reported, glycated haemoglobin was lower at follow-up for most programs, except for The MRTP, where results were mixed following the handover of the program to the Tiwi Health Board when it was incorporate into routine primary health care. Findings relating to estimated glomerular filtration rate (eGFR) are also mixed. Estimated GFR (eGFR) is an important indicator of CKD function but is complicated as a measure of program effect because it can decrease in the short term with use of antihypertensive medications. For many people with CKD, GFR reduces steadily over time, while for others it may follow a non-linear trajectory.(99)

Table 7: Findings on the effectiveness of CKD programs (Q1)

	Tan (2014)		Walker (2013, 2014)		Hotu (2013)		Shephard (2006)		Kondalsamy-Chennakesavan (2003) #1		Kondalsamy-Chennakesavan (2003) #2	
Outcome measure (n)	Baseline (n=43)	17mths (n=39)	Baseline (n=52)	12mths (n=36)	Baseline CC(n=33) UC(n=32)	12mths (n=30) (n=28)	Baseline	15mths	Baseline MRTP(n=149) CCT (n=89)	30mths (n=149) (n=89)	Pre- (n=101)	Post- (n=101)
Systolic Blood Pressure mmHg(SD)	137(17)	126(16)*	153(15)	131(11)*	161(20) 161(20)	140(19) 149(23)**	151(18)	137(18)*	132(22) 126(20)	123(16) 128(16)**	124(14)	129(15)
Median ACR mg/mmol(IQR) #g/day(IQR)	126(65-194)	51(20-97)	34.9 (14.2-150.9) Mean:^ 134.5(286.5)	Median not reported Mean: 44.7(76)*	3.3(1.5-3.2) 1.6(0.9-4.0)	2(0.5-3.8) 3.3(1.5-5.3)**	5.7(1.2-15.2)	4.3(1.3-16.7)	NA	NA	NA	NA
eGFR	68(50-81)	63.1(42-73)*	63.1(20.2)	60.8(18.2)	39(14) 36(15)	41(18) 33(17)	110	118*	NA	NA	NA	NA
HbA1c %(SD)	9.6(24)	8.6(20)*	9.1(14) †	8.0(9) †*	8.3(9) § 8.5(11) §	8.0(10) § 7.9(9) §	NA	NA	NA	NA	NA	NA

*p<0.05 from baseline to follow-up
**p<0.05 program vs. comparator at follow-up in Hotu (2013)
§SE converted to SD (SD=N√SE)
†Mmol/mol converted to %
^Means provided by author. Change per unit per month -0.34 (-0.55, -0.12), p<0.05

Blood Pressure

Detailed blood pressure data are summarised in Table 8, below. Three of the six programs recorded a significant decline in both SBP and DBP from baseline (Shephard et al. 2006; Tan et al. 2014; Walker et al. 2014). Tan et al. (2014) documented an increase from 26% to 56% of patients who met the target BP of ≤ 125/80 mmHg. Both groups in Hotu (2013) achieved significant reductions in SBP, although the end value of the Community Care group was significantly lower than that of the Usual Care group.

Patients managed in the Menzies Renal Treatment Program (MRTP) achieved a significantly greater reduction in both SBP and DBP compared to those managed in the Continuing Care Trial. The proportion of patients with appropriate BP control was also significantly higher in the MRTP cohort (72.4% vs. 59.4% with BP ≤ 140/90 mmHg). Patients managed in the MRTP post-handover of the cohort to the THB had significantly higher BPs than those managed in this cohort prior to its handover. There was also a significant decline in the proportion of clients with appropriate BP control post-handover (60.4% vs. 71% with BP ≤ 140/90 mmHg). However, it should be noted that BP data taken throughout the pre-handover stage of the MRTP reported by Kondalsamy-Chennakesavan (2006) show that mean BPs began to increase prior to handover.

Table 8: Blood pressure findings

Study & BP (mmHg)	Start & sample size	End & sample size	Start & sample size	End & sample size
Tan SBP (±SD) DBP (±SD)	**0 mths** (n=43) 137±17 84±13	**≥17 mths** (n=39) 126±16* 74±13*		
Walker (2014) SBP (±SD) DBP (±SD)	**0 mths** (n=52) 153.0±15.4 90.8±11.9	**12 mths** (n=36) 130.7±10.7[!] 76.3±9.7*		
Shephard SBP (±SE) DBP (±SE)	**0 mths** (n=35) 151±3 92±2	**15 mths** (n=35) 137±3* 84±2*		
Hotu SBP (±SD) DBP (±SD)	**0 mths UC** (n=32) 161±20 85±12	**12 mths UC** (n=28) 149±23* 77±12	**0 mths CC** (n=33) 161±20 88±9	**12 mths CC** (n=30) 140±19*[#] 78±11
Kondalsamy-Chennakesavan SBP (±SD or ±SE) DBP (±SD or ±SE)	**0 mths MRTP** (n=149) 132.4±22.2[$] 77.8±14.5	**30 mths MRTP** (n=149) 123.3±1.3^ 75.2±0.8^	**0 mths CCT** (n=89) 125.5±19.9 78.6±13.8	**30 mths CCT** (n=89) 128.1±1.7 79.9±1.1
 SBP (±SE) DBP (±SE)	**Pre-handover MRTP** (n=101) 124.0±1.4 77.0±0.9	**Post-handover MRTP** (n=101) 129.3±1.5* 80.3±1.1*		

*p<0.05 end vs. baseline; [#]p<0.05 CC vs. UC at 12 months; [$]p<0.05 MRTP baseline vs. CCT baseline; ^p<0.05 MRTP vs. CCT at 30 months. [!]Verbal report from author that this was significant, however p-value was not provided.

Albumin-Creatinine Ratio (ACR)

The preferred method for assessment of kidney damage is albuminuria through the measurement of urine albumin: creatinine ratio (ACR). Albuminuria is defined as an ACR of 3–30 mg/mmol and macroalbuminuria as an ACR of >30 mg/mmol. ACR can be reduced significantly by using anti-hypertensive medications and the target reduction is 50% compared to baseline.(83) Four of the articles reported urinary protein; three used the preferred measure of ACR (Tan et al. 2014; Walker et al. 2014; Shephard et al. 2006) and one measured 24 hour urinary protein (Hotu 2013). Shephard et al. (2006) measured the ACR using morning void urine specimens and Tan et al. (2014) and Walker et al. (2013, 2014) used casual urine samples. The data are reported in Table 9 as either mean urinary protein ±SD or median urinary protein plus IQR.

Both Tan et al. (2014) and Walker et al. (2014) reported a significant decrease in median or mean ACR between baseline and the end of the program. Shephard et al. (2006) reported no significant change in median ACR, but the median baseline value of their patients was in the microalbuminuria range. Hotu (2013) reported a significant increase in urinary protein in the 'usual care' group over the course of the intervention, while the median of those in the 'community care' group fell significantly over the 12 month period and was significantly lower than the median of the 'usual care' group at the end.

Table 9: ACR findings

Study & ACR (mg/mmol) or 24h protein (g/day)	Start & sample size	End & sample size	Start & sample size	End & sample size
Tan (2014) ACR	**0 mths** (n=43) 126 (65–194)	**≥17 mths** (n=39) 51 (20–97)*		
Walker (2014) ACR	**0 mths** (n=52) 134.0±286.5[!]	**12 mths** (n=36) 44.7±76.1*		
Shephard (2006) ACR	**0 mths** (n=35) 5.7 (1.2–15.2)	**15 mths** (n=35) 4.3 (1.3–16.7)		
Hotu (2013) 24h urinary protein	**0 mths UC** (n=32) 1.6 (0.9–4.0)	**12 mths UC** (n=28) 2.2 (0.5–5.1)*	**0 mths CC** (n=33) 3.3 (1.5–5.3)	**12 mths CC** (n=30) 2.0 (0.5–3.8)*[#]

*p<0.05 end vs. baseline; [#]p<0.05 CC vs. UC at 12 months. [!]Results provided by author.

Estimated Glomerular Filtration Rate (eGFR)

For a diagnosis of CKD based on kidney function, eGFR must remain below 60 mL/min/1.73m^2 for a three month period. The Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) formula is currently favoured for calculating eGFR, because it is more precise.(83) Measurements up to 90 mL/min/1.73m^2 are considered reliable. Antihypertensives can cause a reduction in eGFR, the effect of which can take up to two years to stabilize.

Four of the programs reported eGFR as an outcome (Tan et al. 2014; Walker et al. 2014; Hotu 2013; Shephard et al. 2006). Walker et al. (2014) and Tan et al. (2014) both stated that they used the Modification of Diet in Renal Disease formula, while Hotu (2013) and Shephard et al. (2006) did not specify. The eGFR data are reported in Table 10 as either means ±SD or as median plus interquartile range (IQR). There were no details regarding variation around the mean in Shephard et al. (2006).

Table 10: eGFR findings

Study & eGFR (mL/min/1.73m^2)	Start & sample size	End & sample size	Start & sample size	End & sample size
Tan eGFR	**0 mths** (n=43) 68 (50–81)	**≥17 mths** (n=39) 57 (42–73)*		
Walker (2014) eGFR	**0 mths** (n=52) 63.1±20.2	**12 mths** (n=36) 60.8±18.2[!]		
Shephard eGFR	**0 mths** (n=35) 110	**15 mths** (n=35) 118*		
Hotu eGFR	**0 mths UC** (n=32) 39±14	**12 mths UC** (n=28) 41±18	**0 mths CC** (n=33) 36±15	**12 mths CC** (n=30) 33±17

*p<0.05 end vs. baseline. [!]reported as significant change per month, authors provided this data and reported significance but without specific p-value.

Tan et al. (2014) reported a significant reduction in median eGFR between baseline and end, which was particularly evident in the group that achieved remission of albuminuria. However, the decline in the second year was significantly slower than in the first. Shephard et al. (2006) reported a significant increase in eGFR over the course of their program, although the robustness of this result is not known because when measurements of eGFR above 90 mL/min/1.73m^2 occur reasonably often, they are considered unreliable. In this case, the number of measures over 90 was not reported.(83) There was no significant difference between mean eGFR in the randomised control trial (Hotu 2013).

Glycated haemoglobin (HbA1c)

For people with diabetes, blood glucose control significantly reduces the progression of CKD. HbA1c indicates the average plasma glucose concentration over periods of weeks or months and target is under 7.0% or 53 mmol/mol (83). Five of the programs reported HbA1c as an outcome (Tan et al. 2014; Walker et al. 2014; Hotu 2013, Kondalsamy-Chennakesavan 2003). Tan et al. (2014) reported their HbA1c data in mmol/mol and the other three programs reported theirs as a percentage. The data are detailed in Table 11 as mean HbA1c ±SD.

Table 11: HbA1c findings

Study & HbA1c (% or mmol/mol)	Start & sample size	End & sample size	Start & sample size	End & sample size
Tan HbA1c (mmol/mol)	**0 mths** (n=43) 81±24	**≥17 mths** (n=39) 71±20*		
Walker (2014) HbA1c (%)	**0 mths** (n=52) 9.1±1.9	**12 mths** (n=36) 8.0±1.5[!]		
Hotu HbA1c (%)	**0 mths UC** (n=32) 8.5±1.9	**12 mths UC** (n=28) 7.9±1.7	**0 mths CC** (n=33) 8.3±1.6	**12 mths CC** (n=30) 8.0±1.9
Kondalsamy-Chennakesavan HbA1c (%<7%) HbA1c (%<7%)	**pre-handover MRTP** (n=54) 29.8 **MRTP 30 mths** (n=80) 24.3	**Post-handover MRTP** (n=54) 26.2 **CCT 30 mths** (n=39) 30.3		

*p<0.05 end vs. baseline. [!]reported as significant change per month, authors provided this data and reported significance but without specific p-value.

Both Tan et al. (2014) and Walker et al. (2014) reported a significant decrease in mean HbA1c between baseline and end, while there was no significant difference between mean HbA1c in the RCT described by Hotu (2013). Glycaemic control for diabetics in the MRTP pre and post-handover was sustained and there was also no significant difference in glycaemic control between patients managed under the MRTP versus the CCT.

Self-management

Walker et al. (2013; 2014) used the Partners in Health (PIH) instrument(100) to assess changes in patient self-management knowledge, skill and ability, both from the patient's and clinician's perspectives. The PIH has 13 questions, each of which can be scored from 0–8 (i.e. the total score can range from 0–104). In Walker et al. (2013; 2014), patients were assessed at 0, 3 and 12 months. The median score recorded at 0 months was 82 (72–91) and 99 at 12 months, with a mean significant monthly increase of 1.11 units (0.72, 1.50 95% CI; p<0.00005). It is not clear how many patients answered each question at each period of assessment. Over the course of the 12 month program, there was significant improvement in all self-management domains apart from 'I manage the effect of my health conditions on how I feel' (Table 12).

Table 12: Self-management findings

Question	Monthly change in score	95% CI
Overall, what I know about my health condition is: 0 (very little) to 8 (a lot).	0.14*	0.10, 0.18
Overall, what I know about my medication/s and treatment/s for my health condition/s is: 0 (very little) to 8 (a lot).	0.17*	0.12, 0.22
I take my medications or carry out the treatments asked by my health care team: 0 (never) to 8 (always).	0.05*	0.001, 0.09
I share in decisions made about my health condition/s with my health care team: 0 (never) to 8 (always).	0.06*	0.03, 0.1
I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs: 0 (never) to 8 (always).	0.07*	0.03, 0.1
I attend appointments as asked by my health care team: 0 (never) to 8 (always).	0.05*	0.02, 0.07
I keep track of my symptoms and early warning signs: 0 (never) to 8 (always).	0.1*	0.04, 0.16
I take actions when my early warning signs or symptoms get worse: 0 (never) to 8 (always).	0.09*	0.03, 0.15
I manage the effect of my health conditions on my daily physical activities: 0 (not very well) to 8 (very well).	0.11*	0.06, 0.16
I manage the effect of my health conditions on how I feel: 0 (not very well) to 8 (very well).	0.03	-0.02, 0.07
I manage the effect of my health conditions on my social life: 0 (not very well) to 8 (very well).	0.09*	0.03, 0.14
I have enough support from my family/whanau or carers to manage my health: 0 (never) to 8 (always).	0.06*	0.01, 0.11
Overall I manage to live a healthy lifestyle: 0 (not very well) to 8 (very well).	0.06*	0.02, 0.11

*p<0.05 monthly change in score.

Prescribed Anti-Hypertensives and Adherence

The mean numbers of prescribed anti-hypertensives or doses and medication compliance as program outcomes are summarised in Table 13 as percentages or means ±SD. Compliance was not measured using robust methods. Shephard et al. (2006) assessed compliance through monthly tablet counts performed by the clinic nurse and defined compliant patients as those who took at least 80% of their tablets. Hotu (2013) assessed compliance using a questionnaire delivered monthly by the health care assistant which defined compliant patients as those who took their tablets 'most of the time.'

Patients in the programs described by Tan et al. (2014) and Walker et al. (2014) were prescribed a significantly greater mean number of anti-hypertensive medications at the end of the programs compared to the start. The same was true for those patients managed in the 'community care' group of the randomised controlled trial (Hotu 2013). All 35 patients cared for by the Umoona Kidney Project were prescribed anti-hypertensives (Shephard et al. 2006). Compliance to medication levels were high. Shephard et al. (2006) reported 72% and Hotu (2013) reported 80% compliance in the 'community care' group, although compliance in the 'usual care' group was also high.

Table 13: Anti-hypertensive and adherence findings

Study & medications	Start & sample size	End & sample size	Start & sample size	End & sample size
Tan No. antihypertensives	**0 mths** (n=43) 2.7±1.1	**≥17 mths** (n=39) 3.5±0.9*		
Walker (2014) No. antihypertensives	**0 mths** (n=52) 1.9±1.1	**12 mths** (n=36) 2.5±1.2[!]		
Shephard Doses (mg) Compliance	**0 mths** (n=35) None	**15 mths** (n=35) 39% 2 mg; 29% 4 mg;3% 6 mg; 29% 8 mg 72% adherent		
Hotu No. antihypertensives Compliance	**0 mths UC** (n=32) 1.9±0.9	**12 mths UC** (n=28) 2.3±1.0 71% adherent	**0 mths CC** (n=33) 2.2±1.3	**12 mths CC** (n=30) 3.4±1.1* 80% adherent

*p<0.05 end vs. baseline. [!]reported as significant change per month, author provided this figure but p-value not provided

3.5 Results addressing Q2 on costs and cost effectiveness of CKD programs: Study characteristics and findings

3.5.1 Characteristics of studies

Two studies provided evidence relating to costs or cost-effectiveness of CKD programs (Table 14). Both were from the perspective of health services. Baker et al. (2005) measured the cost-effectiveness of the Menzies Renal Treatment Program (MRTP) (a study on the effectiveness of this CKD program (90) was included in the quantitative review), and Gador-Whyte et al. (2014) compared the estimated the costs of delivering best-practice care, as defined by CARPA guidelines(97), with actual expenditure for patients with Type 2 diabetes and/or CKD in an Aboriginal Community Controlled Health Service in remote Central Australia.

Table 14: Characteristics of studies addressing Q2 on costs and cost-effectiveness

Study	Objective	Study Design	Setting	Intervention and Comparator	Comparator	Participants	Outcomes measured
Gador-Whyte et al. (2014) *Cost of Best practice care*	To estimate, from a remote ACCHS perspective, the cost of completing best practice chronic care tasks for patients with type 2 diabetes and/or CKD.[†]	Partial economic evaluation/ costing study.	Australia, remote area; ACCHS in unnamed Central Australian Aboriginal community.	Best practice care for patients with diabetes and/or CKD. .	Usual care delivery for patients with diabetes and/or CKD in that particular ACCHS setting	*Patients*: 205 Aboriginal patients: 74 had diabetes, 86 had CKD and 45 had both. *ACCHS staff*: 4 AHWs, 3 nurses, 1 GP, 1 educator, 1 exercise physiologist. Conducted 2010–2011.	Costs: annual costs (total and per patient) of managing CKD and diabetes in 2009–2010 and projected annual costs using optimal PHC management; difference in these actual and projected costs.
Baker et al. (2005) *Menzies Renal Treatment Program*	To assess, from a government health service perspective, if the MRTP reduced the costs of treating ESKD through improved clinical outcomes.	Economic evaluation.	Australia, remote area; ACCHS on Tiwi Islands, 80 km north of Darwin.	Program to modify kidney and cardiovascular disease. Antihypertensives and health education offered.	Usual Care	*Intervention group*: 258 Aboriginal patients with hypertension and/or CKD. *Comparator group*: 229 Aboriginal patients in a historical control group (1992–1995). Conducted 1995–2000.	Health outcomes: Dialysis starts and dialysis person-years avoided. Costs: MRTP delivery costs; ESKD treatment costs; total cost. Net cost of the program/savings compared to usual care. Measured at 3 and 4.7 years.

3.5.2 Findings on costs and cost effectiveness of CKD programs (Q2)

When comparing the MRTP to usual care, Baker et al. (2005) found that the risk of starting dialysis in the treatment group relative to historical controls over a 4.7 year period was reduced by 57% (p=0.03), as shown in Table 16. Moreover, that over the 4.7 years, 36.8 person years of dialysis were avoided by implementing the MRTP. The reduced number of dialysis starts generated net savings of $4.2 million (in 1997-1998 AUD). Sensitivity analysis indicated that these findings were robust to changes in costing assumptions.

Table 15: Comparison of the effects and costs of the MRTP and control at 4.7 years (Baker et al. 2005)

	MRTP	Control	Difference
Number of client years	897.8	897.8	
Program delivery cost (incremental)	$987,926	$0	$987,926
Endpoint: ESKD treatment			
ESKD treatment years incurred	27.7	64.5	–36.8
ESKD treatment costs incurred	$3,120,350	$7,265,796	–$4,145,446
Total cost (program and ESKD costs)	$4,108,276	$7,265,796	–$3,157,521
Endpoint: dialysis start			
Relative risk for treatment versus control	0.43 (0.19–0.96), p=0.012		
Reduction in risk of starting dialysis in the treatment versus control	57%, p=0.03		
Number of dialysis starts	11	26	–15
Lifetime ESKF treatment costs incurred	$3,853,332	$9,107,875	–$5,254,543
Total cost (program and lifetime ESKD costs)	$4,841,258	$9,107,875	–$4,266,618

Gador-Whyte et al. (2014) reported a total funding gap of $198,728 per annum or $1733 per patient between the projected cost of best practice care and actual expenditure in 2009-2010. No sensitivity analysis was conducted, therefore it is unclear whether funding gaps of similar magnitudes have applied, and continue to exist, in other ACCHS and community settings with different staffing and cost structures.

The study also identified workforce shortages, low health literacy and a high acute care workload as factors that may prevent delivery of best practice care (Table 17).

Table 16: Costs of usual and best practice care for patients in an ACCHS setting (Gador-Whyte et al. 2014)

	Estimated 2009–10 costs ($)		Projected best practice costs ($)		Difference ($)	
Costs for diabetes and CKD care in a remote ACCHS	*Annual*	*Per patient (mean)*	*Annual*	*Per patient (mean)*	*Annual*	*Per patient (mean)*
	446,585	6123	645,313	7856	-198,728	–1733

3.6 Results addressing acceptability and barriers/facilitators of CKD programs (Q3): Study characteristics and findings

3.6.1 Characteristics of studies addressing CKD program acceptability and barriers/facilitators

The two qualitative studies provided evidence addressing the questions of barriers/facilitators of implementation from the perspectives of service providers. One quantitative study addressed the question of acceptability from the perspective of participants in the program (Table 18).

Table 17: Characteristics of studies addressing question 3 on acceptability and barriers / facilitators of implementation

Study	Study Objectives	Study Design	Setting	Participants	Phenomenon of interest addressed
Tchan et al. (2012)	To understand provider views on the implementation of the Outback Vascular Health Service (OVHS), a chronic disease outreach program that operated regularly within the Maari Ma ACCHS	Mixed methods study. Qualitative component used a descriptive, exploratory approach. Semi-structured interviews and inductive analysis. Conducted 2009–2012.	Australia, remote area; ACCHS in Broken Hill and surrounding towns.	20 male and female service providers comprising 4 medical specialists, 6 managers, 2 Aboriginal health workers (AHWs), 5 GPs, 3 local Aboriginal employees.	Facilitators of implementation
Walker et al. (2012)	To understand perceptions of pre-dialysis specialist nurses on factors influencing their delivery of effective pre-dialysis care.	Descriptive, exploratory approach. In-depth semi-structured interviews and thematic analysis guided by Thomas' (2006) general inductive approach.	NZ, variety of areas; pre-dialysis clinics primarily on the North Island.	11 female pre-dialysis nurses working with large case-loads of clients approaching ESKD, including a significant proportion of Māori and Pasifika patients.	Facilitators of implementation
Shephard et al. (2006)	To determine the acceptability of the Umoona Kidney Project: a specialist-run primary health care partnership involving point-of-care testing, specialist visits, education and some outreach.	7-item Cross-sectional survey measured on a 5-point scale and administered by either AHWs, the nurse in charge, community leaders or a medical student	Australia, remote area; ACCHS in Coober Pedy	50 community members including 27 participants in the Umoona kidney program	Acceptability

Tchan et al. (2012) evaluated the Outback Vascular Health Service (OVHS), described as a chronic disease outreach program. The study documents barriers to and enablers of implementing acceptable and effective chronic disease care, including CKD management care to Aboriginal people. Walker et al.

(2012) is a descriptive, exploratory qualitative study describing pre-dialysis nurses' experiences of delivering care to CKD patients on outpatient clinics. While the study does not describe a single CKD management program, it offers evidence relating to barriers and enablers to providing effective pre-dialysis CKD care to Maori and Pasifika patients in outpatient settings in New Zealand, which fits our broad definition of a relevant CKD program. While Question 3 clearly lends itself to qualitative evidence, as a mixed methods review, quantitative evidence from Shephard et al. (2006) is included. This study present the results of a brief survey of program acceptability developed for the Umoona Kidney Program. A 7-item questionnaire was administered to 50 Aboriginal community members, including the participants in the program. Items such as *'Are you happy with the way the kidney team treats you?'* were measured on a 5-point scale from 'very much yes' to 'very much no.'

3.6.2 Findings addressing the question of acceptability and barriers / facilitators of implementation of CKD programs

Twenty-nine findings (themes or concepts identified by the researcher) on enablers of CKD program implementation, all from the perspectives of service providers, were identified and extracted from the two qualitative studies. Of the 29 findings, 17 of the findings had supporting illustrations in the form of participant quotes. All the finding and supporting illustration(s) (where available) are provided in Appendix VIII. The twelve unsupported findings (those without supporting data) in Tchan et al. (2012) were not used in the synthesis. The 17 remaining findings were grouped into four categories defined by similarity of meaning. This process is akin to conducting a second level thematic analysis of the findings across both studies. Each of these categories is described in turn below.

Inter-disciplinary and inter-personal relationships

The importance of interdisciplinary (or inter-professional) and inter-personal relationships as facilitators of the implementation of each of the target CKD programs was emphasised in both studies. Tchan et al. (2012) outlined the importance of relationships at various levels- between specialists and clients, specialists and health service staff and between specialists of different disciplines. These relationships were encouraged and supported within the service structure by conducting specialist visits to the service in week-long blocks to provide time for staff to work together, and encouraging communication between staff by phone and email. Similarly, Walker et al. (2012) described the relationships between nurses and doctors, nursing colleagues, other service providers and *iwi* (tribal) providers as 'fundamental to the delivery of effective pre-dialysis nursing care' (p.31). In both studies, respect, rapport and clear communication were hallmarks of good relationships, and were viewed as key to the provision of coordinated and comprehensive care within the programs themselves, and also in conjunction with other services. Both studies emphasised that such relationships take time to develop, for example, "You really need to spend time to foster the

relationship with the iwi (tribal) providers, the private providers and primary health care people like the GPs and the GPs staff. So I call that a partnership and you've got to spend time networking with them" (p.31)

Implementation of CKD management programs is enabled by embedding the service in trusted, community-owned health care services.

The two findings in this category from Tchan et al. (2012) indicate that embedding CKD programs (including specialist services) within community-owned primary care services, facilitates effective and acceptable CKD management for Indigenous people particularly in rural or remote areas. Doing so enables clients to overcome barriers to accessing CKD management support, such has geographical isolation, mistrust and fear. It allows clients to see specialists in a familiar, culturally-relevant environment close to home: "….not having to leave your family where you are part of your family's support network…it's your sense of wellbeing."(p.23). A long-term commitment from service providers to continue providing the service was also considered essential to overcoming mistrust and having the service accepted as a routine part of the life of the community.

Patient-centred care tailored to the cultural, social, educational and physical needs of individual clients

The findings in this category all reflect, in different ways, the importance of tailoring care to the specific circumstances of each patient. Understanding the cultural, social, educational and physical needs of patients, and having the resources to provide care that addresses those needs, was considered an enabler to implementing effective and acceptable CKD management programs. Findings from Walker et al. (2012) emphasised the importance of service providers having access to cultural resources such as personnel providing cultural support, translators or written resources in different languages when providing effective care to Maori patients, particularly for non-Indigenous service providers. Having the time and flexibility to provide education to patients according to their specific needs was also viewed as a potential enabler of effective care, however a lack of time was viewed as a barrier to achieving this: "We educate them really in a way that is not ideal;. Our resources and time constraints mean we get usually one decent slot of time with the person and we bombard them with a lot of information." (p.30) Tchan et al. (2012) reported that when specialists understood and were able to tailor treatment choices to the individual context of clients, this was an effective approach to working in community. Assertive follow-up of patients enabled them to implement the clinical recommendations provided by specialists and supported them to maintain contact with the CKD management program.

Clinical systems and workplace culture supporting coordinated, multidisciplinary care

Findings under this category relate to the clinical systems and culture that support multidisciplinary, team-based care. In both studies, the importance of nurses, Aboriginal Health Workers (AHWs) and

others working alongside specialists and GPs to provide timely, coordinated and holistic care, was emphasised. Walker et al. (2012) found that while nurses play a key role in patient care, some were frustrated by a perceived lack of autonomy within the hierarchical medical system and saw this as a barrier to the provision of effective healthcare. Barriers to autonomy related to a lack of facilities and a lack of support from doctors (p.32). Findings from Tchan et al. (2012) indicated that when AHWs were encouraged to be present in specialist consultations with patients, informal advice and support provided by specialists was viewed as a facilitator of effective and acceptable CKD care. Having Aboriginal Health Workers in consultations also provided benefits to the specialists in providing a culturally proficient advocate for the patient with knowledge of the local social environment (p.26). This type of multidisciplinary care requires a supportive culture and supportive infrastructure, including appropriate access to patient management systems across disciplines.

These four categories were synthesised into one overall finding, which seeks to provide a useful overall summary of the key findings:

> Service providers identified that implementation of effective and acceptable CKD programs is enabled when coordinated, patient centred care is provided in a trusted, culturally appropriate service setting characterised by: strong, committed inter-disciplinary and inter-personal relationships; and clinical systems supporting multidisciplinary care, with adequate clinical infrastructure.

An overview of this meta-aggregation is provided in Figure 8. The text boxes on the left-hand side show the seventeen findings, classified as either unequivocal (U) or credible (C) and grouped into four categories. These in turn informed the overall synthesised finding.

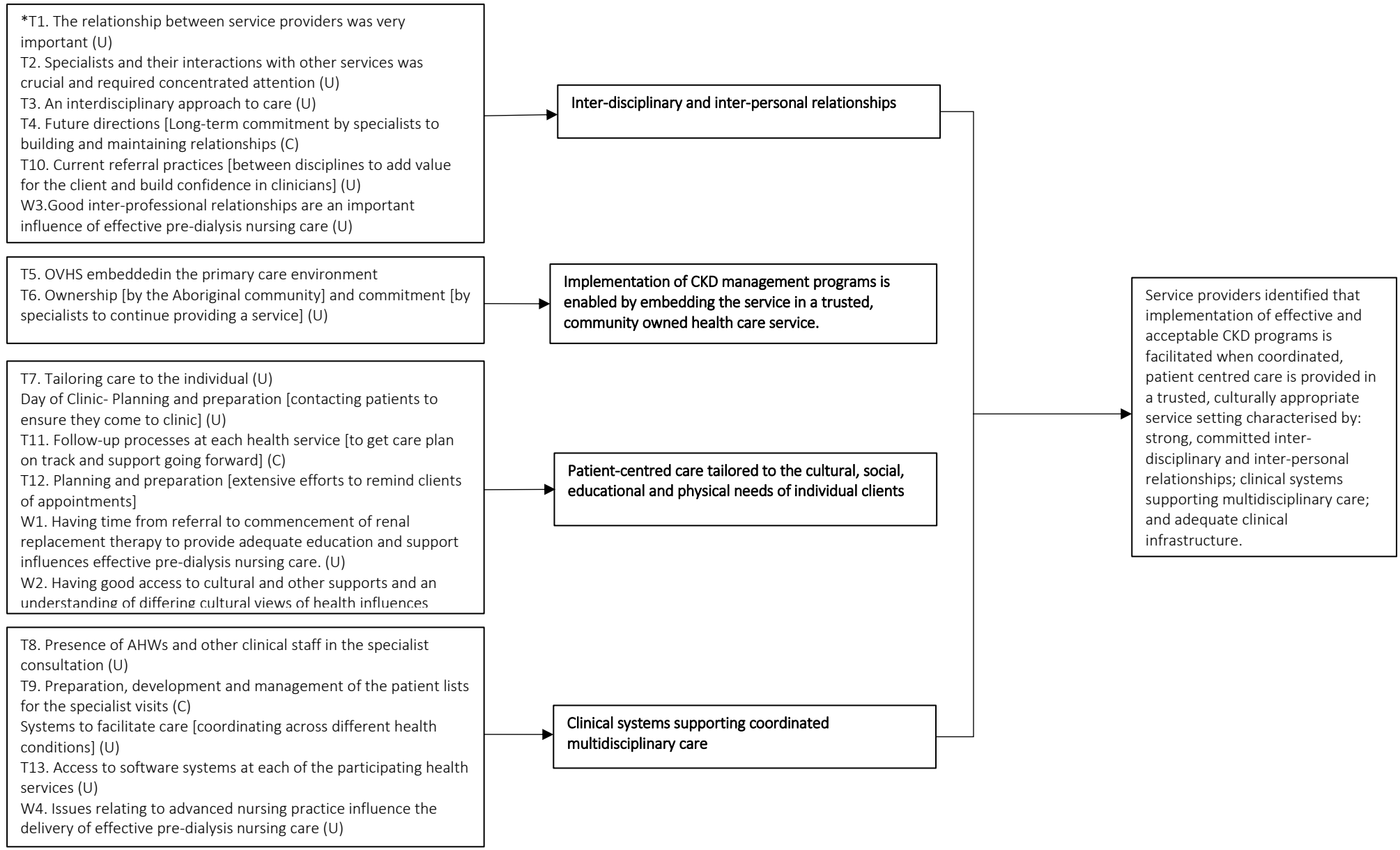

Figure 8: Meta-aggregation of qualitative findings addressing the question of implementation barriers/facilitators of CKD programs (Q3)

The survey of acceptability reported by Shepard et al. (2006), shown below (Table 18) found very positive attitudes amongst community members towards the Umoona Kidney Project. However, the small sample and bias inherent in the phrasing of questions and mode of administration make this questionnaire difficult to interpret with confidence.

Table 18: Acceptability outcomes

Questions	Very much yes	A little bit yes	Don't care	A little bit no	Very much no
Do you worry that you will get bad kidneys? (n=50)	24 (48%)	10 (20%)	1 (2%)	0	15 (30%)
Does your culture make it hard for you to have your kidneys checked (by providing a urine sample)? (n=49)	6 (12%)	2 (4%)	4 (8%)	4 (8%)	33 (68%)
Do you think that people who have their kidneys checked might save themselves from getting sick? (n=49)	46 (94%)	2 (4%)	1 (2%)	0	0
Are you happy with the way the kidney team treats you? (n=40)	38 (95%)	1 (2.5%)	1 (2.5%)	0	0
Do you feel the community is happy about individuals having their kidneys checked? (n=49)	45 (92%)	3 (6%)	1 (2%)	0	0
Do you think the kidney team helps the community? (n=50)	44 (88%)	4 (8%)	2 (4%)	0	0
Do you think the community is happy with the kidney team? (n=44)	33 (75%)	8 (18%)	3 (7%)	0	0

Shephard et al. 2006 provide some limited evidence that a remote-area CKD management program involving specialist visits and regular testing in a primary health care service may be acceptable to participants in the program, and the community more widely. The two qualitative studies provide evidence of facilitators at the level of the type of care provided, service provider characteristics, and clinical systems.

3.7 Summary of Findings Addressing All Questions

A brief overview of the review findings relating to each of the questions is outlined below.

Question 1 *What is the effectiveness of CKD programs designed for Indigenous people in relation to outcomes, including, though not limited to: clinical indicators of CKD management such as blood pressure control; the delayed progression of kidney disease/time to dialysis; and quality of life?*	**Key findings** CKD management programs designed for Indigenous peoples can lead to improvements in clinical indicators of kidney health: ○ Three of the four programs that measured albuminuria reported significant reductions ○ Five of the six that measured BP reported significant declines ○ All four that documented the prescription of antihypertensive medications reported significant increases in numbers prescribed ○ Two of the four that documented HbA1c reported significant falls. CKD management programs designed for Indigenous peoples can lead to the promotion of self-management: ○ The one study that measured self-management reported significant increases in 12 of the 13 domains, suggesting that patients can be willing to change their lifestyles when given support and education ○ The two studies that measured medication adherence reported adherence levels of 72% and 80%.
Question 2 *What are the costs and costs relative to benefits of CKD programs designed for Indigenous people from the perspectives of individual patients and their families, the primary health services that deliver them, tertiary health services and society as a whole?*	**Key Findings** ○ CKD programs tailored to meet the needs of Indigenous people may be cost-effective as they reduce dialysis start numbers, thereby also improving quality of life. ○ Primary health care services may not be adequately funded to provide best-practice care.
Question 3 *What do patient and provider experiences of CKD programs designed for Indigenous people reveal about the acceptability of programs, as well as barriers and facilitators to their implementation?*	**Key Findings** ○ Evidence indicates that a CKD program involving specialist visits in a remote-area primary health care setting may be acceptable to participants and community members. Regarding the barriers and facilitators of implementation, the 17 findings, grouped into four categories, and one synthesized findings indicating that: Service providers identified that implementation of effective and acceptable CKD programs is facilitated when coordinated, patient centred care is provided in a trusted, culturally appropriate service setting characterised by: strong, committed inter-disciplinary and inter-personal relationships; and clinical systems supporting multidisciplinary care, with adequate clinical infrastructure.

Chapter 4: Discussion and Recommendations

4.1 Discussion

The purpose of this review was to examine evidence on the effectiveness, cost effectiveness and acceptability CKD management programs for Indigenous people, as well as barriers and enablers of implementation. These questions were developed in response to a need expressed by service providers working with Aboriginal people in central Australia and were directed at providing guidance for the design and implementation of future CKD programs. The focus of this review was deliberately on a narrow part of what is in reality a continuum of care, from primary prevention and screening, through to dialysis (Figure 2).

Given the broad scope of the questions this review sought to address, the inclusion criteria were inclusive in regards to types of programs, types of outcomes and research design. Within the confines of limitations stemming from the heterogeneity, small sample sizes and moderate quality of the small body of research evidence, the findings indicate that targeted CKD programs are effective in improving clinical outcomes for Aboriginal people with CKD, such as maintaining blood pressure within target ranges and reducing HbA1c and albuminuria. These findings build on the work of Strand and Parker, who conducted an earlier systematic review on the effectiveness of multidisciplinary care compared to standard medical care for people in the pre-dialysis stages of CKD. That systematic review found that multidisciplinary care was effective relative to standard medical care, and that education was an important component of such care.

The evidence base on costs and cost effectiveness of CKD management programs for Indigenous peoples is small when seeking evidence on a narrow part of the CKD treatment continuum. The two studies included in the review were different with respect to study objectives and design, and both of the studies were of moderate quality. In their costing study comparing the projected costs of providing best practice CKD and diabetes care to actual expenditure, Gador-Whyte et al. (92) found that there was a funding short-fall. The short-fall appeared across clinical staff, administrative staff and other operating costs. It was noted that an acute work-load, health literacy, under-staffing and high staff turnover were barriers to the provision of best-practice care, reflecting broader issues such as the challenge of recruiting and retaining staff in remote communities, rather than a funding shortfall per se. One of the valuable contributions of this paper, is its outline of what constitutes best-practice care in a remote Aboriginal Health Service.

The findings of the cost-effectiveness analysis of the Menzies Renal Treatment Program (MRTP) suggest that this program was cost-effective on the basis that it reduced dialysis start numbers. The authors therefore argue that the program was a good investment because they it resulted in reduced

suffering for patients, as well as societal resource savings.(91) The positive impact on quality of life is arguably a sufficient argument for investing in primary and secondary prevention programs. In their systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments, Wyld et al. (101) found that there was indeed a significant decrement of quality of life with dialysis compared with transplantation, and a greater decrement of quality of life with haemodialysis compared with other dialysis modalities. This is relevant to the current study as haemodialysis is the most common form of dialysis taken up by Indigenous Australians, and presents additional disruptions to cultural, social and economic wellbeing due to the need to travel.(20)

There were two qualitative studies and one quantitative survey that partially addressed the question of acceptability of programs, and barriers and facilitators of implementation. These two studies reveal important enablers to implementing CKD management programs to Indigenous people such as governance structures that support community ownership and culturally relevant care; flexible care that can meet the needs of people in their particular context; and robust clinical systems that support communication, staff autonomy and capacity building. The important role of nurses and Indigenous Health Workers was highlighted in both studies. These program features are in line with Gibson et al.(102) who found that community engagement, coordination of care, embedding culturally safe care, for example by employing Indigenous people, and respecting patients' perspectives enabled the implementation of chronic disease care. Excluding IHWs from decision-making and poorly performing electronic support systems were barriers to implementation.

The 17 findings extracted and synthesised from the two qualitative studies on enablers of implementation were from the perspectives of service providers. Regarding the question of acceptability, a survey used in the evaluations of the Umoona Kidney Program provided limited evidence on acceptability of that program from the perspective of participants in the program. The small quantity of research addressing these questions suggests that little is currently known about the how CKD management programs for Indigenous peoples are experienced, in particular from the perspectives of clients, their families or communities. There is comparatively more evidence on the experience of dialysis in both mainstream and Indigenous populations from the perspectives of patients, service providers and family members. (11, 53, 103, 104) These studies emphasise the multiple physical, emotional and practical disruptions that dialysis presents, as well as the adjustments to identity that can be prompted by the commencement of dialysis, providing further support for the argument that more successful management of CKD in the pre-dialysis stage to slow progression of the disease may have multiple benefits.

All CKD programs included in the review were multifaceted, as is commonly the case with chronic disease programs. Researchers have attempted to summarise the necessary elements for successful chronic disease management in models, such as the Wagner Chronic Care Model, to guide clinical practice and health promotion. However, as identified by Davy et al. (105) in their systematic review of the effectiveness of chronic care models, it is not generally possible to identify which combination of chronic care model elements led to improved outcomes. Similarly, in this review it is not possible to draw firm conclusions about the particular components of programs that may be causally related to improved outcomes. Nonetheless, we identified characteristics common to many of the programs.

Common components of effective programs across all included studies were: the integration or coordination with primary care; nurse-led or Indigenous Health Worker-led care; intensive follow-up including home-visits; the provision of anti-hypertensive medication following a step-wise protocol; and addressing barriers to adherence such as cost and lack of transport. In line with Strand and Parker (15), education also emerged as a key component of effective programs, but it had to be delivered in ways that accounted for literacy and culture. Many of these program features also emerged within the findings addressing the question of acceptability, and barriers and enablers of implementation. There is also overlap between these findings and evidence in non-Indigenous populations, which indicates that nurse-led and/or multidisciplinary(15, 106), protocol-driven(107) care embedded in primary health care and including patient education tends to lead to better outcomes.(15, 106, 107)

When interpreting these results, it is important to consider that primary, secondary and tertiary prevention may overlap and there needs to be a good fit between various parts of the treatment pathway to enable the identification of patients, early intervention, effective treatment, with smooth transitions of patients through the system, and efficient use of resources. Also, CKD often co-occurs with other conditions. Within both Indigenous and non-Indigenous populations, CKD is most commonly a secondary complication of diabetes, and high rates of Type 2 diabetes drive the high incidence of CKD. As such, one of the most important strategies for decreasing the burden of CKD in Australia, as elsewhere, is to build the capacity of health services to focus on prevention, early detection and management of diabetes.(108) Lifestyle modification is an important component of prevention activities.

A systematic review of international evidence comparing lifestyle interventions to pharmacological and surgical approaches to prevent progression to type 2 diabetes for those at risk, Stephens et al. found that lifestyle, and some pharmacological, interventions are effective.(109) In line with this, diabetes prevention and management programs tend to focus on lifestyle modification, such as increasing physical exercise, improving nutrition and reducing smoking with a view to modifying

cardio-metabolic risk factors. In a recent systematic review focusing on Indigenous Australians, Schembri et al. (110) reported that nutrition education is an effective strategy for reducing biochemical and anthropometric risk factors. Components of programs considered most strongly associated with positive outcomes in this review were cooking skills workshops, group education sessions and store interventions. The authors concluded that community leadership was key to the implementation of successful programs. Evidence from multiple sources, including the current review, supports the finding that programs that are community owned, that address community priorities and that are implemented according to established community processes, are more effective, as well as being consistent with an ethical imperative for Aboriginal health research to be controlled by Aboriginal people (72, 111)

4.2 Knowledge Gaps

Overall, few studies were found that addressed the review questions and some parts of the questions remain unanswered. In relation to question one, studies reported findings on a number of relevant clinical outcomes, however as noted, none reported findings on hard endpoints such as dialysis starts or death. As such, CKD progression is inferred from clinical indicators and not measured directly. A related issue relates to follow-up times. Most studies were conducted over one or two years, however nephrologists consulted during the course of the review suggested that three years would be the optimum follow-up period.

No studies reported on psychosocial factors such as depression or quality of life. These factors are important in relation to chronic disease where quality of life may be adversely affected, and where emotional distress can impact negatively on disease outcomes both directly and by influencing how a person manages their condition and related lifestyle modifications. The one study that measured self-management reported significant improvement in 12 of the 13 domains, suggesting that patients are sometimes willing to engage in lifestyle modifications when given adequate support and education about management of their condition, combined with empowerment through improved self-management skills.(87) However as a single study, it is difficult to draw conclusions about how lifestyle change and chronic disease management may occur in socially and culturally diverse settings. While there is some evidence relating to how Aboriginal people manage dialysis(12), there is a gap in knowledge about this earlier critical phase of CKD management. Similarly, as the two studies included in the review were from the perspectives of service providers, qualitative evidence from the perspectives of Indigenous people with CKD could provide important information to guide service provision and inform the design of interventions that take account of the social, cultural and physical environment. It may be that more mixed methods CKD program evaluations could begin to address this gap.

4.4 Limitations

This systematic review provides an overview of the available international evidence relating to management programs that have specifically targeted Indigenous peoples with CKD. The JBI approach to systematic reviews ensured the review was conducted with appropriate rigor. The thoroughness of the database and other searches was verified by discussions with experts in the field. Four studies that may have provided additional evidence on the review questions were not accessible. While every effort was made to identify all relevant evidence, accessing all available grey evidence is a challenge that is particularly pertinent to Indigenous health given the extent to which Aboriginal health research remains unpublished or contained in community and organisational reports.

The evidence base on the effectiveness of CKD management programs for Indigenous peoples is limited; heterogeneous with respect to study design, setting, participants, intervention and comparator; and generally of moderate quality (one good, five moderate and one poor quality study that was excluded). Only one of the six included studies of effectiveness was an RCT; the other five programs lacked control groups. Furthermore, apart from the MRTP and CCT (90), the number of participants ranged from 35–65 and the duration of programs from 12–24 months. On account of the small sample sizes and limited follow-up periods, all programs used surrogate outcomes to measure effectiveness, rather than the hard endpoints of dialysis and/or death.

To address the question of cost and cost effectiveness (Q2), we sought to identify studies of CKD management programs that considered cost and cost-effectiveness in their evaluations. Such studies involve weighing up factors and conditions specific to a particular time and context. As such, our ability to draw generalizable conclusions from the two included studies is limited. For example, the effectiveness data in Baker et al.(91) needs to be considered in light of the medical advances that have occurred in routine practice since the data was collected between 1995 and 1998 (although the study was published in 2005). Similarly, Gador-Whyte et al. (92) conducted their study in 2010-2011, and since that time relevant changes to the funding structures of Aboriginal Community Controlled Health Organisations have occurred, such as the introduction of the Practice Incentive Program (PIP) Indigenous Health Incentive, which provides eligible Indigenous health services with a payment for each patient registered for chronic disease care, and an additional payment for those who receive a target level of care in a calendar year.(112, 113) The results of the review overall should be interpreted in light of limits to generalizability and transferability, which also stem from the small and mixed selection of evidence included in the review across all questions.

Finally, the current review attempts to synthesize diverse evidence derived from diverse and often complex Indigenous socio-cultural environments. While there we can assume some similarities between certain contexts, for example, primary healthcare settings have similarities based on their

role and function in a community; there are also differences between settings, based on culture, social circumstances or the physical environment that may be impacting on health outcomes that we cannot know from the published literature. This is true for all research, and the diversity of Indigenous communities serves as a reminder to bring to awareness the assumptions underlying the research or review process. All research represents a snap-shot in time, and the review process in a sense takes research findings 'out of context and then constructs a context.'(114) There are therefore limits to the degree that review findings are representative and transferable; and there is a key role of Indigenous community members and researchers to ensure appropriate interpretation and use of findings. A related limitation of reviews of evidence with Indigenous peoples stems from the use of standardised JBI instruments for critical appraisal, which do not include questions to judge quality from an Indigenous perspective. This issue was recently highlighted by Streak-Gomersall et al.(76) who argue for the development of a specific critical appraisal tool for research involving Indigenous Australians.

4.5 Implications for Practice

We conditionally recommend (JBI Grade B) that:

- CKD programs be tailored to the unique social and cultural needs of Indigenous people, as such tailored programs have been shown to effectively improve outcomes on important clinical indicators of CKD progression and may reduce dialysis starts;
- Primary health care services be adequately funded to provide best-practice care;
- CKD programs be embedded within existing, community governed primary health care services already accessed and deemed acceptable by the target community;
- The role of nurses and Indigenous health workers in clinical decision-making and providing assertive outreach to address barriers to CKD management, be acknowledged, valued and strengthened within CKD management programs; and
- Service providers within CKD programs focus on establishing positive, long-term interpersonal and inter-disciplinary relationships.

4.6 Implications for Research

There is no doubt that more rigorous evaluations of programs over longer time-frames would assist a better understanding the longer-term effectiveness and sustainability of CKD programs, and to understand the mechanisms by which programs lead to change. In complex interventions, the constituent parts of a program may act both independently and inter-dependently.(53) The use of theory to guide the development and implementation of complex interventions is considered good

practice because it can help to predict success and explain failure. In this review, program theories were rarely described, if at all. As such, it is not possible to identify with any confidence which specific program components or strategies were key to achieving improvement in clinical outcomes. Researchers should be encouraged to adhere to best practice by clearly articulating program theories. Doing so would also enable the assessment of program fidelity, and a better understanding of why and how a program effect occurs. This is particularly important given the cultural diversity of Indigenous communities, and the need for programs to be developed *by* or *with* rather than *for* communities. Qualitative research to address the gap in knowledge about how Indigenous people experience and confront barriers to managing CKD and accessing CKD programs would also assist the tailoring of programs to address such barriers.

There is a need for large-scale, long-term, rigorous, community-led research projects to determine the most effective and sustainable CKD management programs for Indigenous people and reduce the need for dialysis. This need should be addressed using either RCT or cluster RCT study designs with larger sample sizes, recruited and followed for sufficient time periods so that the hard endpoints of dialysis and death may be measured. Cost evaluation studies need to accompany these interventions, including calculations relating to costs experienced by individual patients and their families. Such research evidence could be usefully combined with broader evidence on chronic disease prevention and treatment, as well as barriers and facilitators of the implementation of primary health care interventions for Indigenous peoples with chronic diseases, as discussed in both the Central Australia Renal Study (3) and in a recent systematic review conducted by Gibson et al. (102).

4.7 Conclusion

The quantitative, economic and qualitative evidence in this review has provided evidence that CKD programs tailored for Indigenous people may be effective in improving clinical outcomes, may be cost-effective, and has identified several enablers to the implementation of effective and acceptable CKD management programs. There is a need for more and better community-led, long-term research in this area, and the range of questions to be addressed suggests that this research should use mixed methods within a rigorous RCT framework. However, there is also a need for action. Given the human cost of dialysis and the growing population of people living with CKD, it is important that we draw lessons from the available evidence, including this and other sources in Australia and internationally, to provide Indigenous communities with better evidence that can guide the implementation of programs that address the barriers to receiving high-quality care and improve quality of life.

References

1. Australian Institute of Health and Welfare. The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011. Cat. no. IHW 43 Canberra: AIHW, 2011.

2. KHA-CARI. Kidney Health Australia- Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines. Sydney: KHA-CARI.

3. The George Institute for Global Health. Central Australia Renal Study. Canberra: Australian Department of Health and Ageing, 2011.

4. Australian Institute of Health and Welfare. Contribution of chronic disease to the gap in adult mortality between Aboriginal and Torres Strait Islander Australians and other Australians. Canberra: Australian Institute of Health and Welfare, 2011.

5. Burrows NR, Narva AS, Geiss LS, Engelgau MM, Acton KJ. End-stage renal disease due to diabetes among southwestern American Indians, 1990–2001. Diabetes Care. 2005;28(5):1041-4.

6. Naqshbandi M, Harris SB, Esler JG, Antwi-Nsiah F. Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. Diabetes Res Clin Pract 2008;82:1–17.

7. Stewart JH, McCredie MRE, McDonald SP. The incidence of treated end-stage renal disease in New Zealand Maori and Pacific Island people and in Indigenous Australians. Nephrol Dial Transplant. 2004;19:678-85.

8. Pulver LJ, Haswell MR, Ring I, Waldon J, Clark W, Whetung V, et al. Indigenous health - Australia, Canada, Aotearoa New Zealand adn the United States - Laying claim to a future that embracdes health for us all. Geneva: World Health Organisation, 2010.

9. Australian Institute of Health and Welfare. Chronic kidney disease in Aborignal and Torres Strait Islander people 2011. Cat. no. PHE 151 Canberra: AIHW, 2011.

10. Australian Institute of Health and Welfare. Chronic Disease Hospitalisations in Australia 2000-01 to 2007-08. Canberra: Australian Institute of Health and Welfare, 2010.

11. Anderson K, Devitt J, Cunningham J, Preece C, Jardine M, Cass A. If you can't comply with dialysis, how do you expect me to trust you with transplantation? Australian nephrologists' views on indigenous Australians' 'non-compliance' and their suitability for kidney transplantation. Int J Equity Health. 2012;11:21.

12. Burnette LE, Kickett M. Dislocation and Dialysis in Aboriginal Patients with Renal Failure. Aboriginal and Islander Health Worker Journal. 2009;33(4):10.

13. Australian Institute of Health and Welfare. Contribution of chronic disease to the gap in adult mortality between Aboriginal and Torres Strait Islander and other Australians. Canberra: Australian Institute of Health and Welfare, 2011.

14. Howard K, Salkeld G, White S, Chadban S, Craig J, McDonald S, et al. The cost-effectiveness of early detection and intervention to prevent the progression of chronic kidney disease in Australia. Melbourne: Melbourne: Kidney Health Australia, 2006.

15. Strand H, Parker D. Effects of multidisciplinary models of care for adult pre-dialysis patients with chronic kidney disease: a systematic review. Int J Evidence-Based Healthcare. 2012;10:53-9.

16. Rogers A, Kennedy A, Bower P, Gardner C, Gately C, Lee V, et al. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. Med J Aust. 2008;189:521-4.

17. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J, et al. Social networks, social capital and chronic illness self-management: A realist review. Chronic Illness. 2011;7:60-86.

18. Skinner TC, Ellis IK. Tale of Two Courthouses: A critique of the underlying assumptions in chronic disease self-management for Aboriginal people. Australas Med J. 2009;1(12):239-43.

19. Ingram RR. Using Campinha-Bacote's process of cultural competence to examine the relationship between health-literacy and cultural competence. J Adv Nurs. 2012;68(3):695-704.

20. Anderson K, Devitt J, Cunningham J, Preece C, Cass A. "All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease. Med J Aust. 2008;189(9):499-503.

21. Cass A, Lowell A, Christie M, Snelling P, Flack M, Marrnanyin B, et al. Sharing the true stories: Improving communication between Aboriginal patients and the healthcare workers. Med J Aust. 2002;176:466-70.

22. Davidson P, Abbott P, Davison J, DiGiacomo M. Improving medication uptake in Aboriginal and Torres Strait Islander Peoples. Heart Lung Circ. 2010;190(5-6):372-7.

23. Lau P, Pyett P, Burchill M, Furler J, Tynan M, Kelaher M, et al. Factors influencing access to urban general practices and primary health care by Aboriginal Australians - A qualitative study. AlterNative. 2012;8(1):66-84.

24. McGrath P. 'The biggest worry...': Research findings on pain management for Aboriginal and Torres Strait Islander peoples in Northern Territory, Australia. Rural Remote Health. 2006;6(3):549-62.

25. Larkin C, Murray R. Assiting Aboriignal and Torres Strait Islander patients with medication management. Aust Prescriber. 2005;28(5):123-5.

26. Hamrosi K, Taylor SJ, Aslani P. Issues with prescribed medications in Aboriginal communities: Aboriginal health workers' perspectives. Rural Remote Health. 2006;6(2):557-69.

27. Lowell A, Maypilama E, Yikaniwuy S, Rrapa E, Williams R, Dunn S. "Hiding the story": indigenous consumer concerns about communication related to chronic disease in one remote region of Australia. Int J Speech Lang Pathol. 2012;14(3):200-8.

28. Howard K, White S, Salkeld G, McDonald S, Craig JC, Chadban S, et al. Cost-effectiveness of screening and optimal health management for diabetes, hypertension, and chronic kidney disease: a modeled analysis. Value in Health. 2010;13:196-208.

29. Australian Department of Health and Ageing. Central Australia Renal Study: Part 4 Technical Appendices Canberra: The George Institute for Global Health, 2011.

30. Australian Department of Health and Ageing. Central Australia Renal Study: Part 1 Executive Summary. Canberra: The George Institute for Global Health, 2011.

31. Australian Department of Health and Ageing. Central Australia Renal Study Part 1: Key findings, recommendations and implementation plan. Sydney: The George Institute, 2011.

32. Australian Department of Heallth and Ageing. Central Australia Renal Study Part 4: Technical Appendices Canberra: The George Institute for Global Health, 2011.

33. Reilly R, Evans K, Gomersall J, Gorham G, Peters M, Warren S, et al. Effectiveness, cost effectiveness, acceptability and implementation barriers/enablers of chronic kidney disease management programs for Indigenous people in Australia, New Zealand and Canada: a systematic review of mixed evidence. BMC Health Serv Res. 2016;16(119).

34. Evidence-based Medicine Working Group. Evidence-Based Medicine. JAMA. 1992;268(17):2420-5.

35. Montori VM, Guyatt GH. Progress in Evidence Based Medicine. JAMA. 2008;300(15):1814-6.

36. Aromataris E, Pearson A. The systematic review: An overview. Am J Nurs. 2014;114(3):53-8.

37. Montori VM, Saha S, Clarke M. A call for systematic reviews. J Gen Intern Med. 2004;19(12):1240-1.

38. National Health and Medical Research Council. NHMRC additional levels of evidence and grades for recommendations for developers of guidelines: STAGE 2 CONSULTATION. Canberra: NHMRC, 2009.

39. Clarity Informatics. Quality Improvement - A Clinical Analysis UK: Clairy Informatcs 2011 [cited 2015 8th November, 2015].

40. Greenhalgh T, Howick J, Maskrey N, for the Evidence Based Medicine Renaisance Group. Evidence based medicine: a movement in crisis? BMJ. 2014;348.

41. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: What it is and what it isn't. BMJ. 1996;312(7023):71-2.

42. Vijan S, Kent DM, Hayward RA. Are randomized controlled trials sufficient evidence to guide clinical practice in Type II (non-insulin-dependent) deibetes mellitus? Diabetologia. 2000;43:125-30.

43. Cohen AM, Stavri PZ, Hersh WR. A categorization and analysis of the criticisms of Evidence-Based Medicine. Int J Med Informatics. 2004;73:35-43.

44. Hoffman T, Montori VM, Del Mar C. The connection between evidence based medicine and shared decision making. JAMA. 2014;312(13):1295-6.

45. Joanna Briggs Institute. A Strategy for Strengthening the Translation of Evidence into Action Across JBI Programs. Adelaide: The University of Adelaide and Joanna Briggs Institute, 2013.

46. Jordan Z, Lockwood C, Aromataris E, Munn Z. The updated JBI model for evidence-based healthcare. Adelaide: The Joanna Briggs Institute, 2016.

47. The Joanna Briggs Institute. Joanna Briggs Institute Reviewers' Manual: 2014 Edition. Adelaide: The Joanna Briggs Institute; 2014.

48. Oliver S. Advantages of concurrent preparation and reporting of systematic reviews of quantitative and qualitative evidence. J R Soc Med. 2015;108(3):108-11.

49. Pearson A, White H, Bath-Hextall F, Salmond S, Apostolo J, Kirkpatrick P, et al. A Mixed-Methods Approach to Evidence Synthesis. Philadelphia, PA: Wolters Kluwer; 2015.

50. Shemilt I, McDaid D, Marsh K, Henderson C, Bertranou E, Mallander J, et al. Issues in the incorporation of economic perspectives and evidence into Cochrane reviews. Systematic Reviews. 2013;2(83).

51. Higgins JP, Green S, editors. Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. London: The Cochrane Collaboration; 2011.

52. Liberati A, Altman DG, Teare G, Tetzlaff J, Mulrow C, Gotzsche PC, et al. The PRISMA Statement for Reporting Systematic Reivews of Studies that Evaluate Healthcare Interventions: Explanation and Elaboration. PLOS Med. 2009;6(7):e1000100.

53. Centre for Reviews and Dissemination. Systematic Reviews: CRD's guidance for undertaking reviews in health care. Layerthorpe: University of York, 2009.

54. Public Health Agency of Canada. Glossary of Terms Canada2016 [cited 2016 May]. Available from: http://www.phac-aspc.gc.ca/php-psp/ccph-cesp/glos-eng.php#p.

55. Smith V, Devane D, Begley CM, Clarke M. Methodology in conducting a systematic review of systematic reviews of healthcare interventions. BMC Med Res Methodol. 2011;11(1):15.

56. Gomersall J, The Systematic Review of Economic Evidence Working Group. Conducting systematic review of economic evaluations. JBI International Methodology Symposium 2015; Adelaide: Joanna Briggs Institute; 2015.

57. Institute for Evidence-Based Health Professions Education. Chapter 3 - Searching the Literature. Evidence-based Practice for the Health Professions: A free Online Course. Georgia, USA: The Unitversity of Georgia College of Public Heatlh; 2016.

58. Aromataris E, Pearson A. Constructing a search strategy and searching for evidence: A guide to the literature search for a systematic review. Am J Nurs. 2014;114(5):49-56.

59. Whiting P, Savovic J, Higgins JP, Caldwell DM, Reeves BC, Shea B, et al. ROBIS: A new toold to assess risk of bias in systematic reviews was developed. J Clin Epi. 2016;69:225-34.

60. Porritt K, Gomersall J, Lockwood C. Study selection and critical appraisal: The steps following the literature search in a systematic review. Am J Nurs. 2014;114(6):47-52.

61. Munn Z, Tufanaru C, Aromataris E. JBI's systematic reviews: Data extraction and synthesis. American Journal of Nursing. 2014;114(7):49-54.

62. Pang F, Drummond M, Song F. The Use of Meta-analysis in Economic Evaluation. New York: Centre for Health Economics. NHS Centre for Reviews and Dissemination, 1999.

63. Higgins JPT, Green Se. Cochrane handbook for systematic reivews of interventions 5.1.0 [updated March 2011]. London: Cochrane Collaboration; 2011.

64. Hannes K, Lockwood C. Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. J Adv Nurs. 2011;67(7):1632-42.

65. Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: Lessons learnt. BMC Med Res Methodol. 2008;8(21).

66. Pawson R, Greenhalgh R, Harvey G, Walshe K. Realist Review - a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy. 2005;10(S1):21-34.

67. Sandelowski M, Voils CI, Barroso JRS. Defining and Designing Mixed Research Synthesis Studies. Res Schools. 2006;13(1):29.

68. Sandelowski M, Voils CI, Leeman J, Crandell JL. Mapping the mixed methods-mixed research synthesis terrain. J Mixed Method Res. 2012;6(4):317-31.

69. Joanna Briggs Institute Grades of Recommendation Working Party. New JBI Grades of Recommendation. Adelaide: Joanna Briggs Institute; 2013.

70. VicHealth Koori Health Research and Community Development Unit, editor We Don't Like Research...But in Koori hands it could make a difference1999 24 November, 1999. Victoria: VicHealth Koori Health Research and Community Development Unit.

71. Jamieson LM, Paradies Y, Eades S, Chong A, Maple-Brown L, Morris P, et al. Ten principles relevant to health research among Indigenous Australian populations. Med J Aust. 2012;197(1):16-8.

72. National Health and Medical Research Council. Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. Canberra: National Health and Medical Research Council; 2003.

73. Wardliparingga Aboriginal Research Unit. The South Australian Aboriginal Health Research Accord. Adelaide: South Australian Health and Medical Research Institute, 2014.

74. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Government of Canada, 2010.

75. Hudson M, Milne M, Reynolds P, Russell K, Smith B. Te Ara Tika: Guidelines for Maori research ethics: A framework for researchers and ethics committee members. Auckland: Health Research Council of New Zealand, 2010.

76. Streak Gomersall J, Canuto K, Aromataris E, Braunack-Mayer A, Brown A. Systematic review to inform prevention and management of chronic disease for Indigenous Australians: overview and priorities. Aust NZ J Public Health. 2015.

77. King R, Brown A. Next Steps for Aboriginal Health Research: Exploring how research can improve the helaht and wellbeing of Aboriginal people in South Australia. Adelaide: Aboriginal Health Council of South Australia, 2015.

78. Australasian Creatinine Consensus Working Group. Chronic kidney disease and automatic reporting of estimated glomerular filtration rate: New developments and revised recommendations. Medical Journal of Australia. 2012;197(4):1-5.

79. KDIGO. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney Int Suppl. 2013;3:1–150.

80. Diabetes Australia. Blook Glucose Monitoring Melbourne: Diabetes Australia; 2015 [15th December, 2015]. Available from: www.diabetesaustralia,com.au/blood-glucose-monitoring.

81. Reilly R, Evans K, Gomersall J, Gorham G, Warren S, O'Shea R, et al. Effectiveness, cost effectiveness, acceptability and implementation barriers/facilitators of chronic kidney disease management programs and models of care for Aboriginal and Torres Strait Islander Australians: a mixed methods systematic review protocol. The JBI Database of Systematic Reviews and Implementation Reports. 2015;13(4):65-86.

82. JBI. The Joanna Briggs Institute Reviewers' Manual 2014/supplement: Methodology for JBI Mixed Methods Systematic Reviews. Adelaide: The Joanna Briggs Institute, The University of Adelaide; 2014. Available from: http://www.joannabriggs.org/assets/docs/sumari/ReviewersManual_Mixed-Methods-Review-Methods-2014-ch1.pdf.

83. KHA. Chronic Kidney Disease (CKD) Management in General Practice (2nd edition). Melbourne: Kidney Health Australia, 2012.

84. Amega B. The journey may be longer than you think. The Chronicle. 2012;24(3):15-7.

85. Liberati A, Altman DG, Teare G, Tetzlaff J, Mulrow C, Gotzsche PC, et al. The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies that Evaluation Health care Interventions: Explanation and Elaboration. PLoS M. 2009;6(7).

86. Tan J, McCready F, Collins J, Cundy T, Tepueluelu O, Noovao F. Intensification of blood pressure treatment in Pasifika people with type 2 diabetes and renal disease: A cohort study in primary care. NZ Med J 2014;127(1404):17-26.

87. Walker R, Marshall M, Polaschek N. Improving self-management in chronic kidney disease: A pilot study. Renal Soc Australas J. 2013;9(3):116-25.

88. Walker R, Marshall M, Polaschek N. A prospective clinical trial of specialist renal nursing in the primary care setting to prevent progression of chronic kidney disease: A quality improvement report. BMC Fam Pract. 2014;15:155.

90. Kondalsamy-Chennakesavan S. Sustaining renal health outcomes following a community-based intervention program. Darwin: Charles Darwin University; 2003.

91. Baker PR, Hoy WE, Thomas RE. Cost-effectiveness analysis of a kidney and cardiovascular disease treatment program in an Australian Aboriginal population. Adv Chronic Kidney Dis. 2005;12(1):22-31.

92. Gador-Whyte AP, Wakerman J, Campbell D, Lenthall S, Struber J, Hope A, et al. Cost of best-practice primary care management of chronic disease in a remote Aboriginal community. Med J Aust. 2014;200(11):663-6.

93. Hotu C. Optimising blood pressure control in Maori and Pacific patients with type 2 diabetes mellitus and established diabetic nephropathy in New Zealand: The University of Auckland; 2013.

94. Tchan M, Cass A, Buckland A, Kong M. The Outback Vascular Health Service: Evaluation Report. Sydney: The George Institute for Global Health, 2012.

95. Walker R, Abel S, Meyer A. Perceptions of key influences on effective pre-dialysis nursing care. Contemp Nurs. 2012;42(1):28-35.

96. Shephard MD, Allen GG, Paizis K, Barbara JA, Batterham M, Vanajek A. Results of an Aboriginal community-based renal disease management program incorporating point of care testing for urine albumin:creatinine ratio. Rural Remote Health. 2006;6(4):591.

97. Central Australian Rural Practitioners Association. CARPA Standard Treatment Manual (6th Edition). Alice Springs: Central Australian Rural Practioners Association, 2014.

98. Peralta CA, Whooley MA, Shlipak MG. Kidney function and systolic blood pressure new insights from cystanin C: Data from the Health and Soul Study. Am J Hypertens. 2006;19(9):939-46.

99. Li L, Astor BC, Lewis J, Hu B, Appel LJ, Lipkowitz MS, et al. Longitudinal progression trajectory of GFR among patients wiht CKD. Am J Kidney Dis. 2012;59(4):504-12.

100. Battersby M, Ask A, Reece M, Markwick M, Collins J. The Partners in Health scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management. Aust J Primary Health. 2003;9(2&3):41-52.

101. Wyld M, Morton RL, Hayen A, Howard K, Webster AC. A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. PLoS Med. 2012;9(9):e1001307.

102. Gibson O, Lisy K, Davy C, Aromataris E, Kite E, Lockwood C, et al. Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. Implement Sci. 2015;10(71).

103. Rix EF, Barclay L, Stirling J, Tong A, Wilson S. 'Beats the alternative but it messes up your life': Aboriginal people's experience of haemodialysis in rural Australia. BMJ Open. 2014;4.

104. Anderson K, Cunningham J, Devitt J, Preece C, Cass A. "Looking back to my family": Indigenous Australian patients experience of hemodialysis. BMC Nephrol. 2012;13(114):1-15.

105. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, Brown A. Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcomes: a systematic review. BMC Health Servi Res. 2014;15:194.

106. Hopkins RB, Garg AX, Levin A, Molzahn A, Rigatto C, Singer J, et al. Cost-effectiveness analysis of a randomized tiral comparing care models for chronic kidney disease. Clinical Journal of the Am Soc Nephrol. 2011;6:1248-57.

107. Senior PA, MacNair L, Jindal K. Delivery of multifactorial interventions by nurse and dietitian teams in a community setting to prevent diabetic complications: a quality-improvement report. Am J Kidney Dis. 2008;51:425-34.

108. O'Dea K, Rowley K, Brown A. Diabetes in Indigenous Australians: Possible ways forward. Med J Aust. 2007;186(10):494-5.

109. Stevens JW, Khunti K, Harvey R, Johnson M, Preston L, Buckley-Woods H, et al. Preventing the progression of Type 2 diabetes mellitus in adults at high risk: A systematic review and network meta-analysis of lifestyle, pharmacological and surgical interventions. Diab Res Clin Pract. 2015;107(3):320-31.

110. Schembri L, Curran J, Collins L, Pelinovskaia M, Bell H, Richardson C, et al. The effect of education on nutrition-related health outcomes for Aboriginal and Torres Strait Islander people: A systematic review. Aust NZ J Public Health. 2016;40:S42-S7.

111. Reilly R, Doyle J, Daniel M, Aitken L, Atkinson V, Briggs P, et al. A pilot study of psychosocial factors and cardiovascular risk amongst Aboriginal peope living in the Goulburn Valley. J Rural Tropical Public Health. 2011;10:8-14.

112. Australian Governtment Department of Health. Flexible Fund Guidelines: Practice Incentives for General Practices Fund. Canberra: Australian Goverment Department of Health, 2014.

113. Couzos S, Thiele D. The new "Indigenous health" incentive payment: issues and challenges. Med J Aust. 2010;192(3):154-7.

114. Reilly R, Harfield S, Evans K, Peters M, Warren S, O'Shea R et al. Systematic review using the JBI Mixed Method approach: An application using diverse evidence from Aboriginal and Torres Strait Islander healthcare. Presentation at the 2015 JBI international Symposium. Adelaide: 3-4 September, 2015.

Appendix I: Diagnosis of chronic kidney disease

Current guidelines (KHA-CARI 2013) recommend that diagnosis of CKD be based on five stages of kidney function in combination with three stages of kidney damage, as indicated by albuminuria. Increased albuminuria or decreased kidney function increase the risk of adverse renal, cardiovascular and other clinical outcomes (yellow: moderate risk; orange: high risk; red: very high risk). An increased ACR in combination with a decreased GFR multiplies the risk of adverse outcomes, as shown in Table 19.

Table 19: Stages of kidney function used to define chronic kidney disease

Kidney function stage (eGFR mL/min/1.73m²)		**Albuminuria stage (urine ACR mg/mmol)**		
		Normal *<3*	*Microalbuminuria* *3–30*	*Macroalbuminuria* *>30*
1	≥90	Not CKD unless kidney abnormalities present		
2	60–89			
3a	45–59			
3b	30–44			
4	15–29			
5	<15 or on dialysis			

Appendix II: Systematic Review Protocol

Effectiveness, cost effectiveness, acceptability and implementation barriers/facilitators of chronic kidney disease management programs and models of care for Aboriginal and Torres Strait Islander Australians: a mixed methods systematic review protocol

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Review objectives and questions

The objective of this mixed methods review is to synthesize quantitative, economic and qualitative evidence on chronic kidney disease (CKD) management programs and models delivered to Aboriginal and Torres Strait Islander Australians. Studies with Indigenous participants from New Zealand and Canada will also be considered because similar persistent patterns of health inequities have arisen in these countries as a result of a shared colonial history, despite vast differences in timing and location.[1,2] Also, there are geographic and demographic similarities, such as remoteness from health services and poor engagement due to differing language, culture and concepts of health and illness from the dominant culture. These socio-demographic circumstances are associated with higher burdens of chronic disease and poorer health outcomes.[3,4]

The intention of this systematic review is to inform CKD program design, practice and service delivery to Aboriginal and Torres Strait Islander populations in Australia.

The questions to be addressed in the review are:

1. What is the effectiveness of programs/models in relation to outcomes, including, though not limited to, the management of "indicators to target" such as blood pressure control, the delayed progression of kidney disease/time to dialysis, and quality of life?
2. What are the costs and costs relative to benefits of the programs/models from the perspectives of individual patients and their families, the primary health services that deliver them, tertiary health services and society as a whole?
3. What do patient and provider experiences of programs/models reveal about the acceptability of programs, as well as barriers and enablers of implementation?

Background

Chronic kidney disease, and associated chronic illnesses including heart disease, stroke and diabetes, constitutes half of the gap in life expectancy between Indigenous and non-Indigenous Australians.[5] Chronic kidney disease occurs more frequently and in younger age groups amongst Aboriginal and Torres Strait Islander people, with rates three to five times the national average in urban areas and up to 30 times the national average in remote areas.[11] Mortality rates are correspondingly high with reports from Queensland, South Australia, Western Australia and the Northern Territory listing CKD as a primary or associated cause of death in 16% of Indigenous deaths, a rate at least three and a half times higher than the national average.[9] Similarly, a disproportionately high burden of CKD has been found among First Nations people in Canada [6,7] and Maori people in New Zealand.[8]

The scale of the social and economic cost of the progression of CKD to end stage kidney disease (ESKD) in Indigenous Australians is reflected in rates of hospitalization for regular dialysis that are 11 times higher than those recorded for non-Indigenous Australians. Overall, regular dialysis accounts for more than 40% of all hospitalizations for Indigenous Australians.[9] Further, the incidence of ESKD in Aboriginal and Torres Strait Islander Australians has more than doubled between 1991 and 2008 and is projected to increase by 130% from 2009 to 2020.[10] Dialysis is expensive, invasive and leads to decreased quality of life, particularly for Aboriginal people living in rural and remote locations, who often have to leave their homes for extended periods and/or travel long distances to access treatment.[15,16]

High rates of clinical and environmental risk factors, including low birth weight, high blood pressure, obesity, smoking, poor nutrition and socioeconomic disadvantage, contribute to the higher burden of CKD in Indigenous populations.[10] Reducing this burden will require primary prevention strategies across the life course.[11] At present, limited access to appropriate health care in many communities and poor uptake of adult health checks, which partially screen for CKD, present barriers to Aboriginal and Torres Strait Islander Australians accessing timely and appropriate health care for CKD.[5]

While primary prevention and population based screenings are important health priorities for Indigenous populations as they are for the general population, this review focuses on identifying and synthesizing the evidence on programs and models of care for those who have established CKD (see Figure 1). The goals in management of CKD include the reduction of cardiovascular risk particularly through reducing blood pressure to target levels, early detection and appropriate management of complications, avoidance of nephrotoxic medications, timely referral to a nephrologist, health education and support for diet and other lifestyle changes.[12]

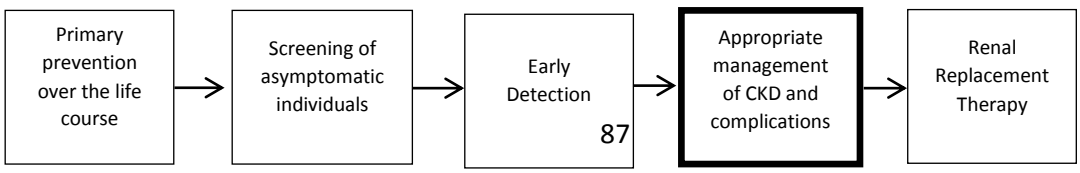

Figure 1: Focus of this review in relation to the prevention and management pathway for CKD

For western, non-Indigenous populations, a recent quantitative systematic review found that care provided by a multidisciplinary team, compared to standard medical care, delays the progression of CKD for adults in the pre-dialysis phase of the condition.[13] The four studies included in that review were conducted within the United Kingdom, United States and Canada and focused on education as the primary preventative strategy. While some aspects of the models shown to be effective in non-Indigenous populations may be effective and acceptable for Aboriginal and Torres Strait Islander populations, the evidence suggests that they should not be wholly transferred. For example, the application of self-management approaches to socially disadvantaged populations has been criticized on the basis that they do not take into account the everyday challenges faced by these population groups.[14,15] In addition, the individualism of western self-management frameworks sits uncomfortably with the more relational social and cultural context of Indigenous people.[16] Further, the ability to access, understand and utilize health information, also known as health literacy, is known to be lower in culturally and linguistically diverse and disadvantaged populations.[17] Health literacy is affected by many factors including language barriers, low educational attainment levels, lack of familiarity with medical terminology and differing styles of learning.

Research has identified that how and where communication occurs affects how information is received and internalized, with patients clearly preferring settings that align with their worldview. Ideally, health education should result in a shared understanding and involve two way communication, rather than a one way imparting of information.[18] This suggests that programs and models of care tailored to the particular needs and context of Indigenous people may be more effective. In order to effectively and appropriately meet the needs of Indigenous people with CKD, programs and models need to fit the social and cultural contexts of Indigenous populations, with a reduced emphasis on the delivery of care within a medical setting.

A recent review of cost-effectiveness of diabetes, hypertension and CKD management programs, conducted in the general Australian population, found that primary care-based screening for CKD and its major risk factors, followed by intensive treatment, can lead to improved health outcomes that are also likely to be good value for money.[19] The Central Australia Renal Study undertook economic analyses of care provided to Aboriginal people in that region and found that the best value for money would be attained through achieving a 20% reduction in the projected rise of ESKD by 2020.[20,21] A key recommendation from this mixed-methods study was to establish a model of service delivery that enabled greater community-based access to dialysis. This model relies on strengthening links between primary community based care and tertiary care, with a focus on prevention.[22]

A preliminary search of the Joanna Briggs Library of Systematic Reviews, the Cochrane Library, CINAHL, PubMed and PROSPERO revealed that there is not currently a systematic review focused on the proposed topic (either published or underway). This review was conducted as part of a larger collaborative research project designed to meet the need of policy-makers for evidence to inform the building of more effective, efficient and appropriate health care programs and models of care. The mixed method design and questions to be addressed in the review arose from consultation with researchers working on this broader project. This review's findings will be used to highlight the common elements and features of successful programs

and provide an evidence informed understanding of key aspects of design and implementation that facilitate success.

This review will consider published and unpublished quantitative, economic and qualitative evidence and use the Joanna Briggs Institute mixed method segregated approach for conducting systematic reviews. There will be two distinct phases in the review process. In phase 1 the quantitative, economic and qualitative evidence relevant to the review questions will be identified, assessed and synthesized in a segregated manner, generating three sets of distinct findings. In phase 2, the results from the three segregated components of the review will be drawn together in an aggregative synthesis.

Definitions

Indigenous: For the purpose of this protocol and systematic review, the term "Indigenous" refers to Aboriginal and Torres Strait Islander Australians, Maori in New Zealand and First Nations people in Canada. Within each of these population groups, there are unique regional and cultural names that are the preferred mode of identifying specific groups. Where possible throughout the systematic review, these names will be used when referring to particular Indigenous subgroup participants of studies.

Chronic kidney disease (CKD): This refers to all kidney conditions resulting in kidney damage and/or reduced kidney function, regardless of underlying cause. It is categorized into five stages according to the degree of reduced function. Stage of kidney disease is commonly diagnosed clinically by the estimated glomerular filtration rate (eGFR). This is measured by using a formula requiring age, gender and serum creatinine level in the blood.[10]

Acceptability: The degree to which a program or model of care is considered acceptable and appropriate by the consumers of care, according to their cultural, social, environmental, geographical, physical and economic needs and preferences.

Barriers and facilitators: Any social, economic, cultural, organizational, environmental or personal factor that inhibits or supports access and/or adherence to the health care treatment or program.

Effectiveness: The effect of the particular program or model of care on the defined outcomes under "real-world" conditions. This is different from the concept of efficacy, which refers to the effect of a program or model of care under ideal conditions.

Cost-effectiveness, cost-benefit and cost-utility analysis: These methods are commonly applied to measure and compare the resource use/costs relative to the benefits/health outcomes/impact of an intervention and comparator. Cost minimization (which assumes benefits are identical for the intervention and comparator) is another method. The approaches are similar (at least in principle) with respect to how they measure cost, but differ in their conceptualization of benefit. The cost benefit approach measures benefits in monetary units, the cost effectiveness approach in natural/clinical outcome units, and the cost utility in quality adjusted life years (QALYS) or disability adjusted life years (DALYS).

Outpatient setting: Care provided to people who are not admitted to hospital. It includes outpatient clinics at hospitals, secondary settings, primary healthcare or community settings and includes outreach services to primary health facilities by multidisciplinary and specialist services.

Program: For the purpose of this review, a program refers to a health sector led sequence of actions or outline of the way a system or service will function, with specifics such as roles and responsibilities, expected expenditures and outcomes defined.

Model of care: a multifaceted concept, which broadly defines the overarching design for the provision of a particular type of health care service. It outlines how healthcare is delivered across clinical streams and patient flow continuums.[23-25]

Inclusion criteria

Types of participants/population

- Indigenous people (adults 18 years or older) of Australia, Canada and New Zealand diagnosed with CKD
  AND
- Receiving care in an outpatient setting.

Studies including participants of other ethnicities (or Australian, Canadian and New Zealand country populations as a whole), other ages or with additional chronic diseases but reporting separately for participants that match the inclusion criteria above will also be considered for inclusion.

In the qualitative component of the review studies including participants who are Indigenous or non-Indigenous family members, significant others, carers and/or health care providers in Australia, New Zealand and Canada reporting on experiences of health care programs/models matching the inclusion criteria will be considered, in addition to studies whose participants match the above criteria.

Types of intervention(s)/phenomena of interest

Studies reporting data on health sector led management programs and models of care explicitly designed to manage, slow progression or otherwise improve the lives of people with CKD will be considered for inclusion.

Studies evaluating renal replacement therapy (dialysis or transplant) will be **excluded**.

With respect to comparators to be considered in the quantitative effectiveness and economic review components, all health care program/model alternatives will be considered, including comparisons with no CKD management program, usual care, non-Indigenous people or all ethnicities in Australia, New Zealand and Canada.

The qualitative component of the review will consider studies that investigate health care worker and/or patient experiences/perceptions of delivery of CKD management programs or models of care to participants matching the inclusion population, in relation to though not limited to, acceptability, patient satisfaction, engagement/participation, self-management and barriers and facilitators of effective CKD management.

Context

All CKD programs or models of care delivered in the **outpatient** setting will be considered.

Types of outcomes

In relation to effectiveness and cost effectiveness, studies will be considered for inclusion if they measure outcomes including, but not limited to:

- Change in clinical indicators such as HbA1c levels and blood pressure control or evaluate outcomes such as survival and rates of progression to ESKD
- Quality of life, acceptability and satisfaction
- Psychosocial and behavioural factors including, but not limited to: ability to self-manage, adherence, depression, anxiety, self-efficacy and service utilization measured with psychometric or other survey instruments
- Barriers and facilitators to implementation
- Costs, and/or costs relative to benefits and/or savings associated with implementing the program/model, only implementing part of the model/program, or doing nothing (no CKD program).

All measures for the range of included outcomes will be considered and, where relevant, limitations of the measures used for example, when an instrument has not been validated for use with Indigenous populations, will be reported.

Types of studies

Studies reporting on primary research will be considered for inclusion.

Studies to be considered in the element of the review addressing the question of effectiveness are:

- Randomised controlled trials (RCTs)
- Non randomised controlled trials
- Observational studies:
    - Retrospective and prospective cohort studies
    - Case control studies
    - Health service studies
    - Health service evaluations
    - Analytic cross sectional studies
    - Descriptive epidemiological study designs

In the component of the review addressing the questions about costs, savings and costs relative to benefits economic evaluations and costing studies (including model based studies)

- All costing and economic evaluation study designs will be included.
- Studies based on empirical data only, or empirical data and modelling will be considered.

The qualitative review component will consider all qualitative study designs including descriptive, ethnography, phenomenology, grounded theory studies, action research and evaluations including developmental evaluation.

If mixed method studies are identified they will be considered for inclusion.

Studies that are systematic reviews, solely prevalence studies or epidemiological studies showing relationships between indicators or risk factors in the absence of a specific program or model of care will not be considered for inclusion.

Search strategy

The search strategy will seek both published and unpublished studies written in English. The date range will be restricted to publications between 2000 and 2014 because technology and data collection in health care has advanced to such an extent that earlier findings are likely to be less relevant in terms of effectiveness, dollar values for cost evaluations and prevailing government strategy, policy and funding arrangements.

A three step search strategy will be used. An initial limited search of PubMed and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies.

The following databases will be searched for published studies:

PubMed

EBSCO CINAHL

Embase

ATSIHealth via Informit online

Web of Science

PsycInfo

Social Science Citation Index

APAIS Health databases

Australian Indigenous Health InfoNet

Primary Health Care Research and Information Service (PHCRIS)

The search for unpublished studies will include:

Mednar and Trove

Google Grey

OCLC WorldCat Dissertations and Theses

Canada Theses Portal

Websites of relevant organizations in each country including Kidney Health Australia, Kidney Health New Zealand and The Kidney Foundation of Canada

Other specific resources to be searched are:

Australian Institute of Torres Strait Islander Studies

llt.Search (Lowitja Institute)

NativeWeb

World Health Organization

Hand searching will include *Pimatisiwin: Journal of Aboriginal and Indigenous Community Health* and reference lists of relevant published systematic reviews.

In addition, relevant experts will be consulted.

Initial keywords to be used will be:

Population of interest

(Australia[mh] OR Australia*[tw] OR Canada[mh] OR Canad*[tw] OR New Zealand[mh] OR New Zealand[tw]) AND (Oceanic ancestry group[mh] OR American Native continental ancestry group[mh] OR aborig*[tw] OR Indigenous[tw] OR Torres Strait Island*[tw] OR Koori*[tw] OR Tiwi[tw] OR Maori[tw] OR First Nation*[tw] OR American Indian*[tw])

Problem of interest

kidney diseases[mh] OR chronic disease[mh] OR chronic kidney[tw] OR chronic renal[tw] OR predialysis[tw] OR pre dialysis[tw] OR albumin creatinine ratio[tw] OR estimated glomerular filtration rate[tw] OR diabetic nephropath*[tw]

Setting/intervention

disease management[mh] OR health services, indigenous[mh] OR rural health[mh] OR rural population[mh] OR rural health services[mh] OR preventive health services[mh] OR community networks[mh] OR delivery of health care[mh] OR health planning[mh] OR intervention[tw] OR management[tw] OR service*[tw] OR model*[tw] OR program*[tw] OR multidisciplinary[tw] OR co ordination[tw] OR coordination[tw] OR integrated[tw] OR transdisciplinary[tw] OR participatory[tw] OR community[tw] OR care[tw] OR prevent*[tw] OR health education[tw] OR health promotion[tw] OR exercise[tw] OR rural[tw] OR outreach[tw] OR remote[tw] OR focus group*[tw] OR ambulatory[tw] OR general practice[tw] OR clinic[tw] OR tertiary[tw] OR primary[tw] OR outpatient[tw] OR telemedicine[tw]

Assessment of methodological quality

Methodological quality of studies selected for retrieval will be assessed by two independent reviewers prior

to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute (JBI).

Quantitative papers will be assessed using the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (Appendix I). Economic papers will be assessed using the JBI Actuari Critical Appraisal tool (JBI-Actuari) (Appendix III). If they include a modelling element, they will also be appraised using the Philips et al.[26] tool for appraising decision analytic models. Qualitative papers will be assessed using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II).

Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer.

Data Extraction

Stage 1 data extraction

Quantitative, economic and qualitative data will be extracted from papers included in the review using the slightly modified data extraction tools from JBI-MAStARI (Appendix IV), JBI-ACTUARI (Appendix V) and JBI-QARI (Appendix VI) respectively. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. In addition, a section of the data extraction tool will be added to record data on elements of programs that are identified as being effective in improving engagement with, uptake of and satisfaction with health services. Authors will be contacted where the need arises, for example to get access to publications or information not reported in the methods and results.

Stage 2 data extraction

Following segregated synthesis of the included quantitative, economic and qualitative evidence, the results of each single method synthesis included in the mixed method review will be extracted in numerical, tabular or narrative format. For example, for syntheses of quantitative data, this will consist of appropriate elements of the meta-analysis Forest plot or, where applicable, an evidence table; for qualitative reviews, it will consist of appropriate elements of the QARI-view table.

Data synthesis

Stage 1 data synthesis for each single-method synthesis

Quantitative papers data will, where possible, be pooled in statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. For included studies on the effectiveness of health care programs/models effect sizes, expressed as odds ratio (for categorical data), weighted mean differences (for continuous data) and their 95% confidence intervals, will be calculated for analysis. Heterogeneity will be assessed statistically using the standard Chi-square test and also explored using subgroup analyses based on the different quantitative study designs included in this review. Where statistical pooling is not possible the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate. The evidence on barriers and facilitators will be described and synthesized in tabular and narrative form.

Economic data from quantitative papers will be synthesized using the "Dominance Ranking Matrix three by three framework" in JBI-ACTUARI, narrative and tables.

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

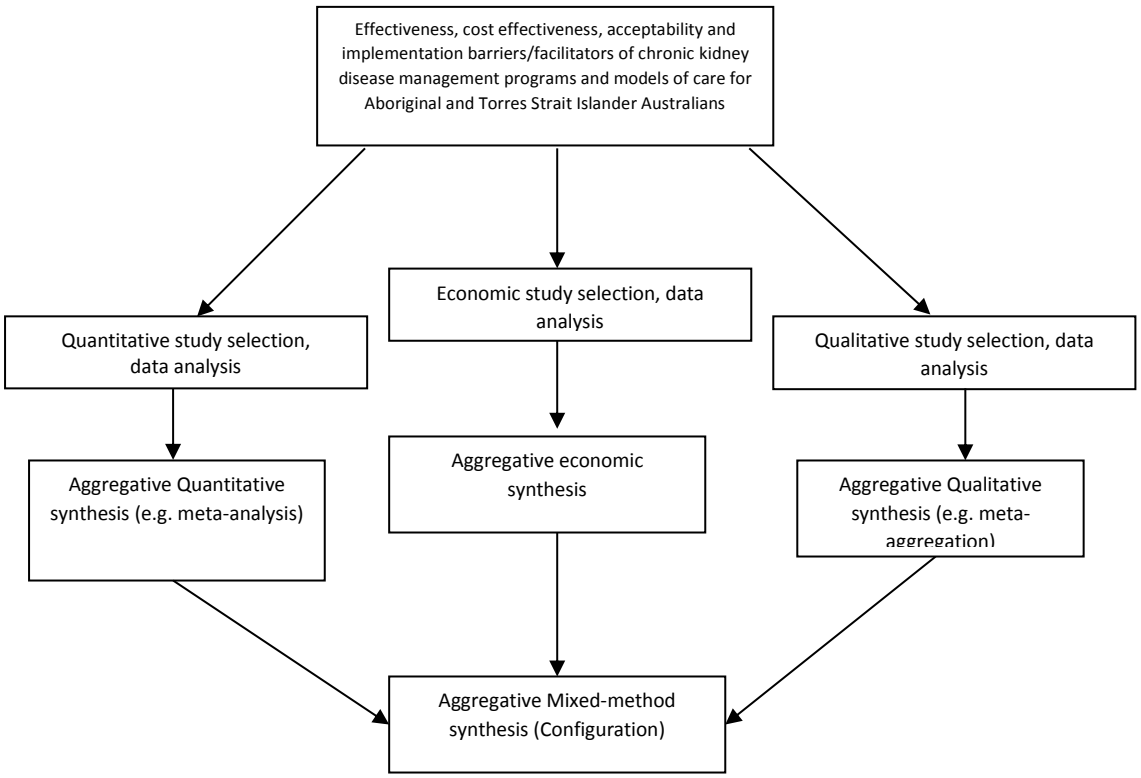

Figure 2: the JBI model of mixed method synthesis

Stage 2 data synthesis for final mixed method synthesis

The findings of each single method synthesis included in this review will be aggregated (Figure 2). This will involve the configuration of the findings to generate a set of statements that represent that aggregation, through coding any quantitative data, attributing a thematic description to all quantitative and textual data; assembling all of the resulting themes from quantitative, qualitative and textual syntheses; and the configuration of these themes to produce a set of synthesized findings in the form of a theoretical framework, set of recommendations or conclusions.

Conflicts of interest

We declare that we have no conflicts of interest.

Acknowledgements

AB is supported by The Sylvia and Charles Viertel Senior Medical Research Fellowship. This project was partially funded by the Australian Government Department of Health. Thanks to Dr Karla Canuto, Assoc Prof Craig Lockwood and Prof Randall Faull for their constructive feedback on the protocol.

References

1. Yeates KE, Cass A, Sequist TD, McDonald SP, Jardine MJ, Trpeski L, et al. Indigenous people in Australia, Canada, New Zealand and the United States are less likely to receive renal transplantation. Kidney Int. 2009;76(6):659-64.

2. Pulver LJ, Haswell MR, Ring I, Waldon J, Clark W, Whetung V, et al. Indigenous health - Australia, Canada, Aotearoa New Zealand and the United States - Laying claim to a future that embraces health for us all. Geneva: World Health Organization, 2010.

3. Pulver LJ, Haswell MR, Ring I, Waldon J, Clark W, Whetung V, et al. Indigenous Health - Australia, Canada, Aotearoa New Zealand and the United States - Laying claim to a future that embraces health for us all. Background Paper, 33. Geneva: World Health Organization; 2010.

4. Yeates KE, Cass A, Sequist TD, McDonald SP, Jardine MJ, Trpeski L, et al. Indigenous people in Australia, Canada, New Zealand and the United States are less likely to receive renal transplantation. Kidney Int. 2009;76(6):659-64.

5. Australian Institute of Health and Welfare. Contribution of chronic disease to the gap in adult mortality between Aboriginal and Torres Strait Islander and other Australians. Canberra: Australian Institute of Health and Welfare, 2011.

6. Burrows NR, Narva AS, Geiss LS, Engelgau MM, Acton KJ. End-stage renal disease due to diabetes among southwestern American Indians, 1990–2001. Diabetes Care. 2005;28(5):1041-4.

7. Naqshbandi M, Harris SB, Esler JG, Antwi-Nsiah F. Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. Diabetes Res Clin Pr 2008;82:1–17.

8. Stewart JH, McCredie MRE, McDonald SP. The incidence of treated end-stage renal disease in New Zealand Maori and Pacific Island people and in Indigenous Australians. Nephrol Dial Transpl. 2004;19:678-85.

9. Australian Institute of Health and Welfare. Chronic kidney disease hospitalisations in Australia 2000-01 to 2007-08. Canberra: Australian Institute of Health and Welfare, 2010.

10. Australian Institute of Health and Welfare. Chronic kidney disease in Aboriginal and Torres Strait Islander people 2011. Cat. no. PHE 151 Canberra: AIHW, 2011.

11. Cass A, Snelling P, Brown A. Preventing chronic disease to close the gap in life expectancy for Indigenous Australians. In: Baur LA, Twigg SM, Magnusson RS, editors. A modern epidemic: Expert perspectives on obesity and diabetes. Sydney: University of Sydney Press; 2012. p. 122-30.

12. Howard K, Salkeld G, White S, Chadban S, Craig J, McDonald S, et al. The cost-effectiveness of early detection and intervention to prevent the progression of chronic kidney disease in Australia. Melbourne: Kidney Health Australia, 2006.

13. Strand H, Parker D. Effects of multidisciplinary models of care for adult pre-dialysis patients with chronic kidney disease: a systematic review. Int J Evidence-Based Healthcare. 2012;10:53-9.

14. Rogers A, Kennedy A, Bower P, Gardner C, Gately C, Lee V, et al. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. Med J Australia. 2008;189:521-4.

15. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J, et al. Social networks, social capital and chronic illness self-management: A realist review. Chronic Illness. 2011;7:60-86.

16. Skinner TC, Ellis IK. Tale of Two Courthouses: A Critique of the Underlying Assumptions in Chronic Disease Self-Management for Aboriginal People. Australasian Med J. 2009;1(12):239-43.

17. Ingram RR. Using Campinha-Bacote's process of cultural competence model to examine the relationship between health literacy and cultural competence. J Adv Nurs. 2012;68(3):695-704.

18. Lowell A, Maypilama E, Yikaniwuy S, Rrapa E, Williams R, Dunn S. "Hiding the story": indigenous consumer concerns about communication related to chronic disease in one remote region of Australia. International J Speech-Lang Path. 2012;14(3):200-8.

19. Howard K, White S, Salkeld G, McDonald S, Craig JC, Chadban S, et al. Cost-effectiveness of screening and optimal health management for diabetes, hypertension, and chronic kidney disease: a modeled analysis. Value Health. 2010;13:196-208.

20. Australian Department of Health and Ageing. Central Australia Renal Study: Part 4 Technical Appendices Canberra: The George Institute for Global Health, 2011.

21. Australian Department of Health and Ageing. Central Australia Renal Study: Part 1 Executive Summary. Canberra: The George Institute for Global Health, 2011.

22. Australian Department of Health and Ageing. Central Australia Renal Study Part 1: Key findings, recommendations and implementation plan. Sydney: The George Institute, 2011.

23. Halcomb EJ, Hickman L, Phillips J, Graham B. Beyond the rhetoric: What do we mean by a 'model of care'. J Adv Nurs. 2006;23(3):3-7.

24. WA Health Networks. Model of Care Overview and Guidelines: Ensuring people get the right care, at the right time, by the right team and in the right place. Perth: Western Australia Department of Health, 2007.

25. Waikato Health Board. Child & Adolescent Clinical Stream: Proposed Model of Care. New Zealand: Health Waikato Division, 2004.

26. Philips Z, Ginnely L, Schulper M, Claxton K, Golder S, Riemsma R, et al. Review of guidelines for good practice in decision-analytic modelling in health technology assessment. Health Technol Asses. 2004;36(8).

Appendix III: Search Strategy

PubMed

Search	*Query*
#1 Population of Interest	(Australia[mh] OR Australia*[tw] OR .au[ad] OR Australia*[ad] OR Northern Territory[tw] OR Northern Territory[ad] OR Tasmania*[tw] OR Tasmania*[ad] OR New South Wales[tw] OR New South Wales[ad] OR Victoria*[tw] OR Victoria*[ad] OR Queensland[tw] OR Queensland[ad] OR Canada[mh] OR Canad*[tw] OR .ca[ad] OR Canad*[ad] OR Alberta[tw] OR Alberta[ad] OR British Columbia[tw] OR British Columbia[ad] OR Manitoba[tw] OR Manitoba[ad] OR New Brunswick[tw] OR New Brunswick[ad] OR Newfoundland and Labrador[tw] OR Newfoundland and Labrador[ad] OR Northwest Territories[tw] OR Northwest Territories[ad] OR Nova Scotia[tw] OR Nova Scotia[ad] OR Nunavut[tw] OR Nunavut[ad] OR Ontario[tw] OR Ontario[ad] OR Prince Edward Island[tw] OR Prince Edward Island[ad] OR Quebec[tw] OR Quebec[ad] OR Saskatchewan[tw] OR Saskatchewan[ad] OR Yukon Territory[tw] OR Yukon Territory[ad] OR New Zealand[mh] OR New Zealand[tw] OR .nz[ad] OR New Zealand[ad] OR Aotearoa[tw]) AND (Oceanic ancestry group[mh] OR American Native continental ancestry group[mh] OR Maori[tw] OR Aborig*[tw] OR indigenous[tw] OR (Torres Strait[tw] AND Islander*[tw]) OR Inuit*[tw] OR eskimo*[tw] OR native[tw] OR First Nation*[tw])
#2 Disease	kidney diseases[mh] OR chronic disease[mh] OR chronic kidney[tw] OR chronic renal[tw] OR predialysis[tw] OR pre dialysis[tw] OR albumin creatinine ratio[tw] OR estimated glomerular filtration rate[tw] OR diabetic nephropath*[tw] OR nephrol*[tiab]
#3 Intervention or setting	disease management[mh] OR health services, indigenous[mh] OR rural health[mh] OR rural population[mh] OR rural health services[mh] OR preventive health services[mh] OR community networks[mh] OR delivery of health care[mh] OR health planning[mh] OR case management[tw] OR intervention[tw] OR management[tw] OR service*[tw] OR model*[tw] OR program*[tw] OR multidisciplinary[tw] OR co-ordination[tw] OR coordination[tw] OR integrated[tw] OR transdisciplinary[tw] OR participatory[tw] OR community[tw] OR care[tw] OR prevent*[tw] OR health education[tw] OR health promotion[tw] OR exercise[tw] OR rural[tw] OR outreach[tw] OR remote[tw] OR focus group*[tw] OR ambulatory[tw] OR general practice[tw] OR clinic[tw] OR primary[tw] OR outpatient[tw] OR telemedicine[tw]
#4	#1 AND #2 AND #3
	Limits: publication date from 01/01/2000–2014; English language.

T

Appendix IV: JBI Critical Appraisal Tools

Quantitative evidence

Randomised controlled trial or pseudo-randomised trial

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Was the assignment to treatment groups truly random?	☐	☐	☐	☐
2. Were participants blinded to treatment allocation?	☐	☐	☐	☐
3. Was allocation to treatment groups concealed from the allocator?	☐	☐	☐	☐
4. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
5. Were those assessing outcomes blind to the treatment allocation?	☐	☐	☐	☐
6. Were the control and treatment groups comparable at entry?	☐	☐	☐	☐
7. Were groups treated identically other than for the named interventions	☐	☐	☐	☐
8. Were outcomes measured in the same way for all groups?	☐	☐	☐	☐
9. Were outcomes measured in a reliable way?	☐	☐	☐	☐
10. Was appropriate statistical analysis used?	☐	☐	☐	☐
	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

Comparable cohort or case control

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is sample representative of patients in the population as a whole?	☐	☐	☐	☐
2. Are the patients at a similar point in the course of their condition/illness?	☐	☐	☐	☐
3. Has bias been minimised in relation to selection of cases and of controls?	☐	☐	☐	☐
4. Are confounding factors identified and strategies to deal with them stated?	☐	☐	☐	☐
5. Are outcomes assessed using objective criteria?	☐	☐	☐	☐
6. Was follow up carried out over a sufficient time period?	☐	☐	☐	☐
7. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
8. Were outcomes measured in a reliable way?	☐	☐	☐	☐
9. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

Descriptive or case series

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Was study based on a random or pseudo-random sample?	☐	☐	☐	☐
2. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
3. Were confounding factors identified and strategies to deal with them stated?	☐	☐	☐	☐
4. Were outcomes assessed using objective criteria?	☐	☐	☐	☐
5. If comparisons are being made, was there sufficient descriptions of the groups?	☐	☐	☐	☐
6. Was follow up carried out over a sufficient time period?	☐	☐	☐	☐
7. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
8. Were outcomes measured in a reliable way?	☐	☐	☐	☐
9. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

_____

_____

_____

Economic evidence

Reviewer _____ Date _____

Author _____ Year_____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there a well defined question?	☐	☐	☐	☐
2. Is there comprehensive description of alternatives?	☐	☐	☐	☐
3. Are all important and relevant costs and outcomes for each alternative identified?	☐	☐	☐	☐
4. Has clinical effectiveness been established?	☐	☐	☐	☐
5. Are costs and outcomes measured accurately?	☐	☐	☐	☐
6. Are costs and outcomes valued credibly?	☐	☐	☐	☐
7. Are costs and outcomes adjusted for differential timing?	☐	☐	☐	☐
8. Is there an incremental analysis of costs and consequences?	☐	☐	☐	☐
9. Were sensitivity analyses conducted to investigate uncertainty in estimates of cost or consequences?	☐	☐	☐	☐
10. Do study results include all issues of concern to users?	☐	☐	☐	☐
11. Are the results generalisable to the setting of interest in the review?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reasons for exclusion)

Qualitative evidence

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

Appendix V: JBI data extraction forms

Quantitative studies

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Method

RCT	☐	Quasi-RCT	☐	Longitudinal	☐
Retrospective	☐	Observational	☐	Other	☐

Participants

Setting

Population

Sample size

Group A _____ Group B _____

Interventions

Intervention A

Intervention B

Authors Conclusions:

Reviewers Conclusions:

Economic studies

Reviewer _____ Date _____

Author _____ Year _____

Journal_____ Record Number _____

Method of Evaluation	Cost Minimisation	☐	Cost Effectiveness	☐
	Cost Utility	☐	Cost Benefit	☐

Interventions

Comparator

Setting

Geographical

Participants

Source of effectiveness data

Authors Conclusions

Reviewers Comments

Extraction Complete Yes ☐ No ☐

Clinical Effectiveness Results

Study design

Year range of primary studies

Analysis used

Clinical outcome results

Economic Effectiveness results

Date/s of economic data

Modeling used

Measure of benefits used in economic evaluation

Direct costs

Indirect costs

Currency

Statistical analysis

Estimated benefits used in EE

Cost results

Synthesis of costs and results

Outcome category

		Clinical effectiveness		
		+	0	–
Cost	+	◉ A	○ B	○ C
	0	○ D	○ E	○ F
	-	○ G	○ H	○ I

Key		
	Effectiveness	Cost
+	Better	Lower
0	Equal	Equal
-	Poorer	Higher

Qualitative studies

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐

Appendix VI: Reasons for Exclusion

The 126 articles excluded after full text review are listed in alphabetical order below.Reasons were one or more of the following:

Not population of interest (eg. Non-Indigenous, or not CKD population)

Not study design of interest (eg. prevalence study)

Duplicate (eg. data presented in both a thesis and journal publication)

Not setting of interest (eg. inpatient setting)

Article inaccessible (ie. could not access after extensive effort)

Article	Exclusion reason 1	Exclusion reason 2	Notes
Anderson, K et al. (2008). '"All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease'. Med J Aust 189: 499–503.	**Population**		Experiences of Indigenous people with ESKD and on dialysis.
Armstrong, B et al. (2007). 'Challenges in health and health care for Australia'. Med J Aust 187: 485–489.	**Design**	**Population**	A review, not CKD population.
Ashton, C, Duffie, D (2011). 'Chronic kidney disease in Canada's First Nations: results of an effective cross-cultural collaboration'. Healthcare Q 14: 42-47.	Design		A screening program with prevalence data only
Australian Commission on Safety and Quality in Health Care (2013). *Vital signs 2013: the state of safety and quality in Australian health care*. Sydney: ACSQHC.	**Design**	Population	A review without a focus on Indigenous people.
Australian Institute of Health and Welfare (2009). *An overview of chronic kidney disease in Australia, 2009*. Cat. no. PHE 111. Canberra: AIHW.	Design		Only reports prevalence data.
Australian Institute of Health and Welfare (2009). *Health care expenditure on chronic kidney disease in Australia 2004–05*. Cat. no. PHE 117. Canberra: AIHW.	Design		Not about programs.
Australian Institute of Health and Welfare (2010). *Expenditure on health for Aboriginal and Torres Strait Islander people 2006–07: an analysis by remoteness and disease*. Cat. no. HWE 49. Canberra: AIHW.	**Design**	Population	A review about chronic diseases in general.
Baeza, J et al. (2009). 'Care for chronic conditions for Indigenous Australians: key informants' perspectives on policy'. Health Policy 92: 211–217.		Population	Not CKD population.
Bailie, R et al. (2006). 'Investigating the sustainability of outcomes in a chronic	Duplicate		Kondalsamy-Chennakesavan (2003)

disease treatment programme'. Soc Sci Med 63: 1661–1670.			was chosen as the most complete account of the MRTP.
Baker, P (2003). *Preventing renal failure in Australian Aborigines: an effective and cost analysis of a screening and treatment program*. PhD thesis, University of Queensland.	Duplicate		Baker et al. (2005) present more data.
Barnett, L, Kendall, E (2011). 'Culturally appropriate methods for enhancing the participation of Aboriginal Australians in health-promoting programs'. Health Promotion J Aust 22: 27-32.	Population	X	Not CKD population.
Baum, F, Fisher, M (2011). 'Are the national preventive health initiatives likely to reduce health inequities?' Aust J Primary Health 17: 320–326.	Design	Population	A review about chronic diseases in general.
Bello, A et al. (2012). 'Use of administrative databases for health-care planning in CKD'. Nephrol Dial Transplant 27 (suppl. 3): 12–18.	Design		A review.
Bruce, S et al. (2010). 'Obesity and obesity-related comorbidities in a Canadian First Nation population'. Chronic Dis Can 31: 27–32.	Design		A screening study with prevalence data.
Bryce, S (2002). 'Lessons from east Arnhem land. Improving adherence to chronic disease treatments'. Aust Fam Physician 31: 617–621.	Design	population	Expert opinion about chronic diseases in general.
Burgess, C et al. (2010). 'Healthy country, healthy people: the relationship between Indigenous health status and "caring for country"'. Med J Aust 190: 567–572.	Design		Cross sectional study looking at associations rather than a program.
Burke, H et al. (2005). *Maari Ma Chronic Disease Strategy: while prevention is better than cure, control is better than complication*. Maari Ma: Maari Ma Health Aboriginal Corporation.	Design		A report on a strategy with no outcome data.
Campbell, D et al. (2011). 'Potential primary health care savings for chronic disease care associated with Australian Aboriginal involvement in land management'. Health Policy 99: 83–89.	Design		Based on a cross sectional study looking at associations rather than a program.
Canadian Institute for Health Information (2013). *End-stage renal disease among Aboriginal peoples in Canada: treatment and outcomes.* Ottawa: CIHI.	Population	Design	Renal replacement treatment and not about a program.
Canadian Institutes for Health Research, the Canadian Society of Nephrology, the Kidney Foundation of Canada and CANN-NET (2014). *Developing a Canadian research*	Design	Population	Outlines strategy and gaps with no focus on Indigenous people.

strategy in pre-dialysis chronic kidney disease: a planning document.			
Central East Local Health Integration Network (2010). *Chronic kidney disease initiatives promising practice report.* Ontario: Central East LHIN.	Design	Duplicate	Prevalence data that are also reported in Ashton and Duffie (2011).
Chadban, S et al. (2010). 'Cost-effectiveness and socioeconomic implications of prevention and management of chronic kidney disease in type 2 diabetes'. Nephrology 15: S195–S203.	Design		A review.
Chalmers, R et al. (2012). 'Flying nephrologists – remote renal outreach clinics in the Top End'. Nephrology 17: 68.	Design		A conference abstract about a service.
Collins, J et al. (2007). 'DEFEND: a community-based model of care to improve blood pressure control in Māori and Pacific patients with diabetic nephropathy'. Nephrology 21: A8.	Duplicate	Design	A conference abstract that reports results of the same CKD program as Hotu (2010).
Collister, D et al. (2010). 'Creating a model for improved chronic kidney disease care: designing parameters in quality, efficiency and accountability'. Nephrol Dial Transplant 25: 3623–3630.	Population		The proportion of First Nations people was minor and incidental: 13% pre-intervention; 8% post-intervention.
Connors, C (2011). 'Chronic disease in the Northern Territory (NT): improving Aboriginal health through a systems approach'. Internal Med J 41: 34.	Population	Design	A conference abstract about chronic diseases in general.
Cooperative Research Centre for Aboriginal Health (2008). *Chronic conditions program statement*. Canberra: CRCAH.	Population	Design	A research statement about chronic diseases in general.
Couzos, S et al. (2008). 'Chronic kidney disease'. In *Aboriginal primary health care: an evidence-based approach* (3rd edition). South Melbourne: Oxford University Press.	Population		A book chapter.
Deved, V et al. (2013). 'Quality of care for First Nations and non-First Nations people with diabetes'. Clin J Am Soc Neph 8: 1188–1194.	Design		No evaluation of a program.
Edwards, L (2013). 'NT chronic conditions prevention and management strategy annual report 2011'. The Chronicle 25: 29–30.	Design	Population	A strategy document about chronic diseases in general.
Egan, R et al. (2014). 'Spiritual care and kidney disease in NZ: a qualitative study with New Zealand renal specialists. Nephrology 19: 708–713.	Setting	Population	Hospital based with patients receiving renal replacement therapy or palliative care.
Gao, S (2006). *Chronic kidney disease among First Nations people in Alberta: prevalence, health services utilization and*	Design		No program outcomes reported.

access to quality care. PhD thesis, University of Calgary.			
Gao, S, et al. (2008). 'Access to health care among status Aboriginal people with chronic kidney disease. Can Med Assoc J 179: 1007–1012.	Design	Duplicate	No program outcomes reported and paper associated with Gao (2006) thesis.
Gittelsohn, J et al. (2010). 'Participatory research for chronic disease prevention in Inuit communities. Am J Health Behav 34: 453–464.	Population		Not CKD population.
Gordon, R, Richards, N (2012). 'The Chronic Care for Aboriginal People program in NSW'. NSW Public Health Bull 23: 77–80.	Design	Population	No program outcomes reported and about chronic diseases in general.
Gorham, G (2003). *Prevention and treatment options for renal disease in the Northern Territory (with particular reference to the Barkly region)*. Casuarina: Cooperative Research Centre for Aboriginal and Tropical Health.	Population	Design	About patients on renal replacement therapy and no program outcomes reported.
Gorham, G (2010). 'Renal Indigenous resources project'. The Chronicle 16: 19.	Design		Brief article announcing availability of resources.
Gracey, M et al. (2006). 'An Aboriginal-driven program to prevent, control and manage nutrition-related "lifestyle" diseases including diabetes'. Asia Pac J Clin Nutr 15: 178–188.	Design	Population	Prevalence data and not CKD population.
Harch, S et al. (2012). 'Management of type 2 diabetes: a community partnership approach'. Aust Fam Physician 41: 73–76.	Design	Population	Focus on diabetes and process data.
Harris, S et al. (2013). 'Type 2 Diabetes in Aboriginal peoples'. Can J Diabetes 37: S191–S196.	Design	Population	A review about diabetes.
Harvey, P et al. (2013). 'Chronic condition management and self-management in Aboriginal communities in South Australia: outcomes of a longitudinal study'. Aust Health Rev 37: 246–250.	Population		Not CKD population.
Helps, Y, Kowanko, I (2011). *Riverland Aboriginal chronic disease support group community storybook 2011.* Melbourne: Aboriginal Health Council of South Australia,.	Design	Population	Stories of experiences of living with diabetes.
Hotu, C et al. (2010). 'A community-based model of care improves blood pressure control and delays progression of proteinuria, left ventricular hypertrophy and diastolic dysfunction in Māori and Pacific patients with type 2 diabetes and chronic kidney disease: a randomized controlled	Duplicate		Hotu (2013) presents additional information.

trial'. Nephrol Dial Transplant 25: 3260–3266.			
Howard, K et al. (2006). *Cost-effectiveness of early detection and intervention to prevent progression of chronic kidney disease in Australia.* Kidney Health Australia.	Population	Design	Does not report results for Aboriginal sub group and is not about individual CKD programs.
Hoy, W et al. (2000). 'Reducing premature death and renal failure in Australian Aboriginals. A community-based cardiovascular and renal protective program'. Med J Aust 172: 473–478.	Setting		Kondalsamy-Chennakesavan (2003) was chosen as the most complete account of the MRTP.
Hoy, W et al. (2001). 'Renal disease and the environment: lessons from Aboriginal Australia'. Nephrology 6: 19–24.	Design	Duplicate	A review that includes the MRTP.
Hoy, W et al. (2003). 'Reduction in natural death and renal failure from a systematic screening and treatment program in an Australian Aboriginal community'. Kidney Int 63: 66–73.	Duplicate		Kondalsamy-Chennakesavan (2003) was chosen as the most complete account of the MRTP.
Hoy, W et al. (2003). 'Secondary prevention of renal and cardiovascular disease: results of a renal and cardiovascular treatment program in an Australian Aboriginal community'. J Am Soc Nephrol 14: S178–185.	Duplicate		Kondalsamy-Chennakesavan (2003) was chosen as the most complete account of the MRTP.
Hoy, W et al. (2004). *Final report on the Aboriginal Chronic Disease Outreach Program*. Brisbane: Centre for Chronic Disease, University of Queensland.	Design		Prevalence data.
Hoy, W et al. (2005). 'A chronic disease outreach program for Aboriginal communities'. Kidney Int Suppl S76–82.	Design	Duplicate	Prevalence data reported in other Hoy papers and reports.
Hoy, W et al. (2005). 'Clinical outcomes associated with changes in a chronic disease treatment program in an Australian Aboriginal community'. Med J Aust 183: 305–309.			Kondalsamy-Chennakesavan (2003) was chosen as the most complete account of the MRTP.
Hoy, W et al. (2006). *Western Australian Chronic Disease Outreach Program: Bega Garnbirringu Health Service, final report.* Brisbane: Centre for Chronic Disease, University of Queensland and Kidney Disease Research and Prevention.	Design	Population	Process data about chronic diseases in general.
Hoy, W et al. (2007). *Western Australian chronic disease outreach program: Broome Regional Aboriginal Medical Service final report.* Brisbane: Centre for Chronic Disease, University of Queensland and Kidney Disease Research and Prevention.	Design	Population	Process and prevalence data about chronic diseases in general.

Hoy, W et al. (2010). 'Chronic disease profiles in remote Aboriginal settings and implications for health services planning'. Aust NZ J Public Health 34: 11–18.	Design	Duplicate	Prevalence data reported in other Hoy papers and reports.
Hoy, W et al. (2014). 'Evidence for improved patient management through electronic patient records at a Central Australian Aboriginal Health Service'. Aust NZ J Pub Health, 38: 154–159.	Population	Design	Not CKD population and prevalence data.
Hunter New England Area Health Service (2006). *Aboriginal Renal Disease Prevention and Education Program.* NSW Health.	Inaccessible		Internet link broken.
Illawarra Health. *Aunty Jean's Good Health Team: listening to the voices of the Elders to create an Aboriginal chronic and complex care program.* Unanderra: Illawarra Health.	Population		Not specifically CKD population, no outcomes/relevant experiential data reported.
Jeffries-Stokes, C et al. (2011). 'A complex Aboriginal health project and the challenges for evaluation'. Aust NZ J Pub Health 35: 204–206.	Design		Expert opinion.
Johnson, D, Mathew, T (2007). 'Managing chronic kidney disease'. Medicine Today 8: 37–45.	Inaccessible		No link to article on journal website.
Jones, R et al. (2002). 'Point-of-care in Aboriginal hands'. Aboriginal and Islander Health Worker J 26: 13–16.	Design		Limited prevalence data.
Kamaladasa, Y et al. (2013). 'Investigating barriers to effective predialysis planning of Pacific Islander patients in western Sydney'. Nephrology 18: 65.	Population	Design	A conference abstract about people who had commenced dialysis.
Katz, I et al. (2006). 'Chronic kidney disease management – what can we learn from South African and Australian efforts?' Blood Purif 24: 115–122.	Design	Duplicate	A review that refers to the MRTP.
Kenealy, T et al. (2010). 'Systematic care to reduce ethnic disparities in diabetes care'. Diabetes Res Clin Pract, 89: 256–261.	Population		Not CKD population.
Khalil, H (2011). 'Reduction of salt intake for the prevention and treatment of diabetic kidney disease'. Aust Pharmacist 30: 291.	Design	Population	A summary of a systematic review with no mention of Indigenous people.
Khalil, H et al. (2013). 'Managing chronic diseases in rural aged care facilities using point-of-care testing systems'. Rural and Remote Health 13: 2597.	Design	Population	A review of point of care testing for chronic diseases in general.
Kidney Health Australia (2013). *Charting a comprehensive approach to tackling kidney disease: "proposals to guide increased risk assessment, support early detection and improve the treatment of kidney disease":*	Design		A planning document.

pre-budget submission 2013-2014 federal budget. Melbourne: Kidney Health Australia.			
Kidney Health Australia (2013). *Tackling kidney disease: a national action plan to reduce Australia's kidney disease burden.* Melbourne: Kidney Health Australia.	Design		A planning document.
Kidney Health for Life (2014). *Chronic Kidney Disease Multinational Inventory*. Kidney Health for Life.	Design	Population	An international inventory of CKD care and burden.
Kowanko, I et al. (2012). *Chronic condition management strategies in Aboriginal communities: final report 2011.* Adelaide: Flinders University and the Aboriginal Health Council of South Australia.	Population		Not CKD population.
Ludlow, M et al. (2013). 'Key to good health: assessing the effectiveness of community screening for chronic kidney disease'. Nephrology 18: 33.	Design		A conference abstract about screening.
Majoni, W (2011). 'Telemedicine is crucial for improving access to specialist renal care and management of renal disease in remote/rural locations'. Internal Med J 41: 11.	Design		A conference abstract. Emailed author who replied saying that no data to report.
Maniapoto, T, Gribben, B (2003). 'Establishing a Māori case management clinic'. NZ Med J 116: U328.	Population	Design	An early progress report of a chronic diseases clinic.
Marley, J et al. (2012). 'Quality indicators of diabetes care: an example of remote-area Aboriginal primary health care over 10 years'. Med J Aust, 197: 404–408.	Population		Not CKD population.
McCready, F et al. (2013). *Report on chronic kidney disease project – Langimalie Clinic*. Unpublished.	Duplicate		Data published in Tan et al. (2014).
McDermott, R, Segal, L (2006). 'Cost impact of improved primary level diabetes care in remote Australian indigenous communities'. Aust J Primary Health 12: 124–130.	Population		Not CKD population.
Mead, E et al. (2013). 'A community-based, environmental chronic disease prevention intervention to improve healthy eating psychosocial factors and behaviors in indigenous populations in the Canadian Arctic'. Health Educ Behav 40: 592–602.	Population		Not CKD population.
Murrumbidgee Local Health District (2014). *Murrumbidgee Local Health District renal clinical service plan 2013–2017*. Wagga Wagga: Murrumbidgee Local Health District.	Design		A planning document.
New South Wales Health (2003). *Draft NSW Aboriginal chronic disease service framework: cardiovascular disease, diabetes, kidney disease, chronic respiratory*	Inaccessible		Could not find internet link.

disease and cancer. North Sydney: NSW Health.			
New South Wales Health (2010). *Kidney Health Check: promoting the early detection and management of chronic kidney disease*. North Sydney: NSW Health.	Design	Setting	Policy directive for a hospital setting.
Nolte, E, McKee, M (2008). *Caring for people with chronic conditions: a health system perspective*. Geneva: Open University Press.	Design	Population	A review for policy making in Europe.
Northern Territory Government (2005). *Renal Services Strategy.* Darwin: NTG.	Design		A strategy.
Northern Territory Government (2012). *Renal Services Framework 2012–2017.* Darwin: NTG.	Design		A strategy.
O'Sullivan, B et al. (2014). 'Adoption, implementation and prioritization of specialist outreach policy in Australia: a national perspective'. Bulletin WHO 92: 512–519.	Design	Population	Describes a World Health Organization policy and not CKD population.
O'Sullivan, C et al. (2004). 'Everybody's business'. Nephrology 9: S117–S120.	Design		Expert opinion.
Paasse, G, Adams, K (2011). 'Working together as a catalyst for change: the development of a peer mentoring model for the prevention of chronic disease in Australian Indigenous communities'. Aust J Prim Health 17: 214–219.	Design	Population	A descriptive article and not CKD population.
Peiris, D (2010). *Chapter 6: What influences access to health services for Indigenous peoples in Australia, New Zealand, Canada and USA? A qualitative systematic review utilising candidacy theory and focusing on chronic illness care*. PhD thesis, *Building better primary care systems for indigenous peoples: a multimethods analysis,* University of Sydney.	Design	Population	A systematic review about chronic diseases in general.
Queensland Aboriginal and Islander Health Council (2014). *External Report 3 Aboriginal and Islander Controlled Health Services Clinical Excellence (ACE) Program*. South Brisbane: Data Management Unit, Preventative Health Unit,	Design		An audit.
Queensland Health (2010). *The health of Queensland's Māori population 2009.* Brisbane: Queensland Health.	Design		No program evaluated.
Rae, K et al. (2014). 'Long conversations: Gomeroi gaaynggal tackles renal disease in the Indigenous community'. Aust Epidem 21: 44–48.	Design	Population	The developmental factors leading to CKD.

Reeve, C et al. (2008). Indigenous Lifescripts – a tool for modifying lifestyle risk factors for chronic disease. Aust Fam Physician 37: 750–751, 753–754.	Design	Population	Describes a tool and not CKD population.
Robinson, R et al. (2003). *A follow-up study of outcomes of the Tiwi Renal Treatment Program.* Darwin: The Centre for North Australian and Asian Research and The Cooperative Research Centre for Aboriginal and Tropical Health.	Duplicate		Kondalsamy-Chennakesavan (2003) was chosen as the most complete account of the MRTP.
Sav, A et al. (2013). '"You say treatment, I say hard work": treatment burden among people with chronic illness and their carers in Australia'. Health Soc Care Comm 21: 665–674.	Population		The treatment burden of chronic diseases in general.
Saweirs, T (2012). *Diabetes and chronic kidney disease pilot Northland, December 2010–December 2012: Final report.* Unpublished.	Population		Although the intervention targeted 'two practices with above average % of Māori patients', no details provided about participants' ethnicities. No email response from author.
Schmidt, B et al. (2012). 'Getting better at chronic care in remote communities: study protocol for a pragmatic cluster randomised controlled of community based management'. BMC Public Health 12: 1017.	Design	Population	A study protocol about diabetes care.
Schneider, J (2007). *Manitoba Renal Program's renal health outreach: shifting the paradigm.* In: *Canadian Association of Nephrology Nurses and Technologists 2007*, 17: 25, Winnipeg, Manitoba.	Design		A conference abstract.
Scott, M (2001). 'NSW Aboriginal Vascular Health Program'. Aboriginal and Islander Health Worker J 25: 28.	Design	Population	Entirely descriptive and not CKD population.
Sharma, S et al. (2010). 'Addressing the public health burden caused by the nutrition transition through the Healthy Foods North nutrition and lifestyle intervention programme'. J Hum Nutr Diet 23 suppl 1: 120–127.	Design	Population	Entirely descriptive and not CKD population.
Shephard, M (2007). *The development and application of point-of-care pathology testing (POCT) models for the early detection and management of diabetes and renal disease in indigenous medical services*. PhD thesis, University of Adelaide.	Duplicate		Data also reported in Shephard et al. (2006).
Shephard, M et al. (2000). 'The Umoona Kidney Project'. Aboriginal and Islander Health Worker J 24: 12–15.	Duplicate	Design	Mostly descriptive and data also reported in Shephard et al. (2006).

Shephard, M et al. (2005). *A preventative model for Aboriginal renal disease.* Adelaide: Renal Unit, Flinders Medical Centre and Umoona Tjutagku Health Service.	Inaccessible		No internet link.
Shephard, M, et al. (2003). 'Albuminuria in a remote South Australian Aboriginal community: results of a community-based screening program for renal disease'. Rural & Remote Health 3: 10.	Design		Prevalence data.
Shephard, M, Gill, J (2005). 'An innovative Australian point-of-care model for urine albumin: creatinine ratio testing that supports diabetes management in Indigenous medical services and has international application'. Ann Clin Biochem 42: 208–215.	Design		A review about point of care testing.
Si, D et al. (2010). 'Assessing quality of diabetes care and its variation in Aboriginal community health centres in Australia'. Diabetes-Met Res Rev 26: 464–473.	Design	Population	An audit of diabetes care.
Simmons, D (2003). 'Impact of an integrated approach to diabetes care at the Rumbalara Aboriginal Health Service'. Internal Med J, 33: 581–585.	Design	Population	An audit of diabetes care.
Smith, R et al. (2011). 'Analysis of a primary care led diabetes annual review programme in a multi ethnic cohort in Wellington, New Zealand'. Diabetes Res Clin Pract, 91: 164–170.	Population		Not CKD population.
Taylor, S et al. (2013). 'Diabetes in Torres Strait Islanders: challenges and opportunities for remote area nurses'. Contemporary Nurse, 46: 46–53.	Design	Population	A review of diabetes care.
Terare, M et al. (2012). 'The chronic care service enhancement program'. NSW Public Health Bull, 23: 58–59.	Design	Population	A short description of a program. Not CKD population.
The George Institute (2011). *Central Australia Renal Study.* Canberra: Australian Department of Health and Ageing.	Population	Design	Focus is renal replacement therapy and does not describe individual programs.
The Kidney Foundation of Canada (2014). *Developing a Canadian research strategy in pre-dialysis chronic kidney disease: a planning document.*	Design	Population	A planning document with no mention of Indigenous people.
The Lowitja Institute (2010). *Cost-effectiveness of interventions for kidney disease: renal replacement therapy and screening and early treatment of chronic kidney disease*.	Design		A pamphlet that refers to Vos, T et al. (2010). *Assessing cost-effectiveness in prevention.* University of Queensland, Brisbane and Deakin University, Melbourne,

			which is about government guidelines.
Thomas, M (2005). 'Deprivation and dialysis: pathways to kidney failure in Australian Aborigines'. Adv Chronic Kidney Dis 12: 84–87.	Design		Expert opinion.
Tracey, K et al. (2013). 'A nurse-managed kidney disease program in regional and remote Australia'. Renal Soc Aust J 9: 28–34.	Design	Population	A description of a program mostly for patients on dialysis.
van Holst Pellekaan, S, Clague, L (2005). 'Toward health and wellbeing for Indigenous Australians'. Postgrad Med J 81: 618–624.	Design		A review.
Virani, S et al. (2006). 'Rationale and implementation of the SLICK project: screening for limb, I-Eye, cardiovascular and kidney complications in individuals with type 2 diabetes in Alberta's First Nations communities'. Can J Public Health 97: 241–247.	Design	Population	A diabetes screening program.
Vos, L et al. (2013). 'Addressing chronic kidney disease in Far North Queensland: gains and opportunities'. Aust J Rural Health 21: 313–318.	Design		An audit.
Wakerman, J et al. (2005). 'Sustainable chronic disease management in remote Australia'. Med J Aust 183: S64–68.	Design	Population	A review about chronic diseases in general.
Walker, R, Voss, D (2009). 'Mate tākihi ukiuki making a difference in chronic kidney disease'. BPJ 22: 24–37.	Design		An educational resource.
Ward, D et al. (2013). 'Assessment of the Siksika chronic disease nephropathy-prevention clinic'. Can Fam Physician 59: e19–25.	Population		Not CKD population.
Wardman, D (2008). *Chronic kidney disease and Aboriginal people: disabling or enabling?* Presentation at British Columbia Nephrology Days meeting.	Design		Not about a program.
Weeramanthri, T et al. (2002). 'Chronic disease guidelines and the Indigenous Coordinated Care Trials'. Aust Health Rev, 25: 1–6.	Design	Population	Guidelines about chronic diseases in general.
Weeramanthri, T et al. (2003). 'The Northern Territory preventable chronic disease strategy – promoting an integrated and life course approach to chronic disease in Australia. Aust Health Rev, 26: 31–42.	Design	Population	A strategy about chronic diseases in general.
Weil, E, Nelson, R (2006). 'Kidney disease among the indigenous peoples of Oceania'. Ethn Dis, 16: S2 24–30.	Design		Expert opinion

Whalley, W, Mathew, R (2006). 'Island Lake Regional Renal Health Program: prevention and treatment closer to home'. CANNT Journal 16: 20.	Design		A conference abstract about a program but no data presented.
White, Y (2012). *Self-reported physical activity, health related quality of life and emotional well-being in end stage chronic kidney disease*. PhD thesis, University of Wollongong.	Setting	Population	Exercise routines within a renal unit and no Indigenous subgroup.
Wise, M et al. (2013). *National appraisal of continuous quality improvement initiatives in Aboriginal and Torres Strait Islander primary health care*. Melbourne: The Lowitja Institute.	Design		An appraisal of CQI initiatives in Indigenous primary health care settings in general.
Zeunert, S et al. (2002). 'Nutrition project in a remote Australian Aboriginal community'. J Ren Nutr 12: 102–106.	Population	X	Not CKD population because only 25% of participants had CKD.

Appendix VII: Key components of programs described in the quantitative studies

Study	Key elements of programs
Tan et al. (2014)	▪ **Nurse-led integrated care** also involving a **GP** and **specialist** in a **primary care setting** (p. 23) ▪ **Tongan-speaking staff** well connected to community (p. 18) ▪ **Intensive follow-up** including **home visits** (p. 18) ▪ **Antihypertensive** medication stepwise **protocol** (p. 18) ▪ Focus on **improving medication adherence** (p. 18) ▪ **Lifestyle, diet** and **self-care education** (p. 18) ▪ **Up-skilling** of primary care clinicians (p. 24).
Walker et al. (2013, 2014)	▪ **Specialist nurse-led collaborative care** also involving **GPs** and **nurses** in a **primary care setting** (2014, p. 12) ▪ **Self-management** and **education** focus (2013, p. 116) ▪ **Intensive follow-up** including **home visits** (2013, p. 117) ▪ **Free assessments, medications** and **transport** (2014, p. 2, 4) ▪ **Antihypertensive** medication stepwise **protocol** (2014, p. 4) ▪ **Adequate time** allocated to nurses (2013, p. 119) ▪ **Nurses empower patients** to self-manage because more approachable than doctors (2013, p. 119) ▪ **Up-skilling** of primary care clinicians and **enhanced linkages** between **primary care** and the regional **secondary nephrology service** (2014, p. 12).
Hotu (2013)	▪ **Nurse-led integrated care** also involving a **GP** and **HCAs** (p. 70) ▪ **Māori** and **Tongan HCAs** fluent in their own languages (p. 70) ▪ **Intensive follow-up** by HCAs including **home visits** (p. 70) ▪ **Effective recall** system (p. 101) ▪ **Antihypertensive** medication stepwise **protocol** (p. 82) ▪ **Medication adherence promoted** by HCA (p. 80) ▪ Individual **education** sessions (p. 80) ▪ **Free transport** and **subsidised medications** (p. 70) ▪ **Frequent communication** among medical team (p. 80)
Shephard et al. (2006)	▪ Promoted **community awareness, involvement and ownership** of the project, which led to a **high level of trust** between renal team and community members (p. 8) ▪ **Family-orientated** for both adults and their children (p. 8) ▪ Advice from visiting **specialists** in **primary care setting** (p. 8) ▪ **Training empowered AHWs** (p. 8) ▪ ACR testing timed to enhance **accuracy** and the **immediacy of POCT** results meant patients could **quickly see the specialist** and have their **treatment modified** (p. 8) ▪ Use of **POCT** not only raised awareness of CKD but also facilitated the development of **nutrition-centred health programs** (p. 8).
Kondalsamy-Chennakesavan (2003)	▪ **Visiting specialist led** involving a team of visiting **nursing coordinators** and locally based **AHWs** in a **primary care setting** (p. 3, 8) ▪ Focus on **antihypertensive medications** with **stringent application** of **guidelines** (p. 16) ▪ **Individual treatment plans** (p. 3) ▪ **Systematic recall** and **intensive follow-up** (p. 11) ▪ **Health promotional counselling** (p. 11).

Appendix VIII: List of qualitative findings

Findings from Tchan et al. (2012)

The Outback Vascular Health Service evaluation report. Maari Ma Health Aboriginal Corporation, Broken Hill.

Findings were classified as U (unequivocal) or C (credible) based on the strength of the supporting illustration.

Finding (Tchan et al.)	Illustration
Finding 1: The relationship between service providers was very important (U, p. 19–20). **A number of factors were considered integral to fostering good working relationships between local staff and visiting specialists:** • **'Visits were conducted in one-week blocks providing a solid presence and opportunity for the specialist and local staff to work together'** • **'Email and phone contact was encouraged by the specialists and valued by local staff'** • **'An AHW sitting in on consultations was strongly encouraged by specialists and community health service management.'** **In addition, the personalities of the specialists were considered a good fit to the Aboriginal community working environment. Institutional links were seen as an enabler of ongoing, sustainable service by training doctors who might meet future demand.**	*I think a process like this either succeeds or fails on the basis of the characteristics and personality of the people involved* (manager, p. 20). *For the long term, you want to be able to be self-sustaining and be able to turn people through. This is almost certainly what the focus on the institutional links is all about, trying to get people from registrar level through, you know, so that you start getting a turnover of consultants appearing that are familiar with it and might take up that burden (*specialist, p. 20*).*
Finding 2: Specialists and their interactions with other services (U, p. 20). **Each of the specialties has different needs and referral pathways to secondary and tertiary services such as other medical physicians, surgeons and hospital care. Communication and relationship building between the OVHS and other secondary and tertiary services was critical and required concentrated attention.**	*…as a specialist you let people know what the opportunities are and what the possibilities are, so you have to move that horizon up to doing things which are not available anywhere near the place where they live. And then it becomes an idea of 'how do they get there, how do you move these people to where the higher stuff is?' That's a particular cardiology problem* (specialist, p. 20).

Finding 3: An interdisciplinary approach to care (U, p. 21). **An interdisciplinary approach to care provides benefits in the form of supportive specialist input into patient care. However, such care requires additional coordination and a lack of such coordination can present a barrier to optimal care.**	*...his [the renal specialist's] input is fantastic, so I tend to use him more as a general physician – his advice about anything is good, so I don't restrict my patients to purely renal* (GP, p. 21).
Finding 4: Future directions (C, p. 22). **The commitment of specialists to service provision over the long-term was highlighted. This was reported in relation to 'the importance of continuing to building ownership and trust within the Aboriginal community,' maintaining 'positive and strong relationships between specialists, and health service staff;' 'valuing the impact such relationships have on the day to day functioning of the service;' and 'building better relationships with tertiary services...'**	*I have a long-term view. I think you don't get anything unless you plug away at it. If you give up too early, that's what's wrong, it is hard you know* (specialist, p. 22).
Finding 5: OVHS embedded in the primary care environment (U, p. 23). **'Significant benefits flowed from the specialist service being embedded in the primary care environment. It serviced a community that traditionally has difficulties accessing specialist services due to geographical isolation, financial barriers, mistrust and fear. OVHS clients saw specialists in an environment that was familiar to them.' Other benefits noted included opportunities for capacity building and exchange, and for knowledge translation by having Aboriginal health workers sitting in consultations and interacting in other ways.**	*There are obvious benefits, you know having your specialists in your community, it's not having to wait on long waiting lists and it's not having to leave your family where you are part of your family's support network...it's your sense of wellbeing. Yeah, so I think it is those three things and I'm sure anyone would appreciate having that opportunity* (Aboriginal staff member, p. 23). *For the community, if you can imagine someone living in an isolated town then having to go on a bus on their own, especially an elderly person, that wasn't approved an escort, it's not that good. You get bad outcomes - really bad outcomes. That patient will go home and never see the doctor again. These are the sort of things that happen out here* (senior staff member, p. 23). *Sitting in the consult serves two purposes, it's training our staff, but it's also support for our*

	community because sometimes language may be used that needs to be broken down (senior AHW, p. 23). *It is not that they're on their own...they're part of a team and we're part of the process also, and I think that's the most important thing. And if the patient doesn't understand what the specialists are talking about, that is when we step in. And put it in layman's terms; bring it down a bit, not up here* (AHW, p. 23).
Finding 6: Ownership and commitment (U, p. 23–24). **Ownership of the Aboriginal CKD program by the local ACCHS was seen as an overarching strength of the program.**	*Oh I think there's a real ownership from Maari Ma; I think they love their OVHS team, or are getting to love them ... so I think its service is now branded with Maari Ma and I think that's a great part of it* (GP, p. 23). *Aboriginal people have a hard time trusting service providers and so it will take a commitment from the service providers to continue to offer a service before it becomes acceptable as part of the lifestyle of our community* (senior Aboriginal manager, p. 24). *...the OVHS is providing the message to the community that Maari Ma which is owned by the community, is providing the opportunity for those specialists to come to our communities* (senior Aboriginal manager, p. 24).
Finding 7: Tailoring care to the individual (U, p. 24). **It was felt that the specialists were getting more of a feel for the patient's lifestyle so the disease was being treated in the context of lifestyle rather than simply based on clinical guidelines.**	*…they do actually get to know the person and how they interact with their environment* (GP, p. 24). *And so I think the specialists have understood, and they give management to our patients (not necessarily based on the current clinical evidence base), but on what's actually going to work, what's going to be used* (GP, p. 24).

Finding 8: Presence of AHWs and other clinical staff in the specialist consultation (U, p. 26). **Exposure to, and communication with, specialists provides opportunities for up-skilling and support. Informal advice and support provided by specialists to Aboriginal health workers in their clinical decision making was viewed as an enabler of effective and acceptable CKD care. Participants communicated with GPs and specialists via telephone and email and used a case study to illustrate how emailing a photo of a condition led to timely and appropriate care for a patient. Participants also described benefits from other clinical staff, including Aboriginal health workers, learning by attending consultations conducted by specialists. Having Aboriginal Health Workers in consultations also provided benefits to the specialists in providing a culturally proficient advocate for the patient with knowledge of the local social environment.**	*…the more staff are exposed to that level of expertise, the more they become familiar with those different health conditions as well* (senior staff member, p. 26). *...you get to see them operate as a team and I think that has been a real bonus to observe their particular interaction because these guys are highly skilled, competent people. We can learn from that...* (local Aboriginal health service manager, p. 26). *...it's certainly something that will be amazing if our local workers got that level of skill and could provide support to the specialist. And support to the GPs in fact. And we know, we're not quite there yet so having these guys come out from RPA [Royal Prince Alfred Hospital, Sydney] and be able to role model that kind of team approach and team work, I think that's kind of ideal* (local Aboriginal health service manager, p. 26). *In a cross-cultural setting there is a lot that our culturally confident employees can teach these guys as well, because these guys are used to dealing with the mainstream and not dealing with the sensitive nature of Aboriginal people living in rural and remote Australia*... (senior local Aboriginal health service manager, p. 26).
Finding 9: Preparation, development and management of the patient lists for the specialist visits (C, p. 27). **Coordination and management of specialist clinics could be assisted by a 'clinical go-to person.' The coordination and management of the CKD program would be assisted by a relatively autonomous clinical staff member, such as a GP registrar or diabetes clinical nurse consultant, working in conjunction with administrative staff and other team members to**	*A clinical go-to person would add value to the OVHS service. They would need to be clinically based, for example a medical registrar or experienced RN [registered nurse], who can make clinical decisions regarding patients. The current coordinator could work closely with the clinician to assist in decision-making* (GP, p. 27).

complete a number of tasks before, during and after clinics.	
Finding 10: Current referral practice (C, p. 28). **GPs tend to refer based on their clinical expertise, their knowledge of the clients or guideline oriented need for specialist review, rather than clearly defined criteria that could be systematically described. The role of the specialist could also be viewed as one supporting the decision-making capabilities of other clinical staff.**	*So the reason I refer is I tend to look at what value can be added, and that goes through cycles. So for example, now with the diabetes, because they've been coming less time than the other specialists, we've got loads of diabetics that still need to go through that basic assessment process, but we will come to the end of that and then it will be less focused maybe on new patients and more focused on follow-up* (GP, p. 28). *...you see patients but the more important thing is skills and knowledge transfer...it's more about making other clinicians confident in doing things they probably already need to do* (specialist, p. 28).
Finding 11: Follow-up processes at each health service (C, p.30). **Broken Hill Primary Care Service: The multidisciplinary team worked alongside the GP to provide active patient follow-up.**	*…it's a team effort to get that patient back in, get their care plan back on track and then provide what support we can to the patients going forward*...(local Aboriginal health service staff member, p. 30).
Finding 12: Planning and preparation (U, p. 31). **Planning and preparation for clinics involved extensive efforts to remind clients of appointments, arrange transport and attend to all other preparatory clinical work.**	*I'm conscious of the fact that we work really hard to make sure that the clinics are full when the specialists come and that takes a lot of effort.* (local Aboriginal health service manager, p. 31). *So the ones that I know it's urgent for them to come up, they'll get reminded the day before with an appointment slip and I'll arrange for them to be reminded again that morning and again later in the morning in some cases*...(Local Aboriginal health service staff member, p. 31).
Finding 13: Access to clinical software systems at each of the participating health services (U, p. 31). **Shared clinical software was seen as a benefit to CKD care.**	*I can go back and look in the scanned documents and see what their cardiologist thought of their echo from two years ago. So the electronic medical record is very useful*... (specialist, p. 32).

	...once we got our heads around Medical Director [software] it was fine - it took us a little while because we don't use it but it's good to be able to access the patients' notes (specialist, p. 32). *Well I like it because it's keeping it in the clients' notes isn't it, it's keeping it in the family...* (GP, p. 32).

Unsupported findings from Tchan et al. (2012)

These findings were not accompanied by illustrations.

Finding (Tchan et al.)	**Description**
OVHS and the isolated patient travel and accommodation scheme (p. 21).	The process for arranging patient travel to major metropolitan hospitals for treatment has been complicated.
*Up-skilling and support (p. 24).	The importance of education, up skilling and support to Maari ma GPs and clinical staff were acknowledged and prioritised…
Case management via videoconference (p. 24).	The videoconference case management sessions were seen as important …. and their role has become clear and functionality improved over the years.
Informal clinical advice and support (p. 25).	Support and advice via email and telephone was highly regarded.
Verbal handover versus traditional setters – an innovative method of communication (p. 25).	In keeping with the objective of upskilling staff, OVHS specialists provided face-to-face handover of their clinical recommendations to the multidisciplinary team.
Role of the central coordinator (p. 27).	The role of the central coordinator is described.
Coordination and management of OVHS clinics (p. 27–28).	The central manager improved the coordination of the OVHS.
Support the clinic on the day (p. 28).	The local manager and the nominated clinician should share coordination and management on the day.
Overall maintenance and monitoring of patient lists (p. 28).	The collection of data is essential for quality improvement and evaluation purposes. Maintenance of this should be the role of the administrator.
Appointment lists (p. 29).	There was no systematic process to establishing the client appointment list. Creation of the list was considered time consuming but necessary.

Future direction (p. 29).	There needs to be systematic process for creating the appointment list. GPs need to ensure a referral letter is written for each new OVHS client. Creating systematic processes for appointment lists would assist data collection and should be the responsibility of the central coordinator.
Systems to facilitate care (p. 30).	This finding describes the development of spreadsheets by GPs and registrar, the employment of a diabetes CNC and the role of the multidisciplinary team in the follow-up of clients.

*the importance of up skilling is also incorporated in Finding 7, above.

Findings from Walker et al. (2012)

Perceptions of key influences on effective pre-dialysis nursing care. *Contemporary Nurse,* 42(1): 28–35.

Finding (Walker et al.)	Illustration
Finding 1: Time with patients (U, p. 30). **Having time from referral to commencement of renal replacement therapy to provide adequate education and supports influences effective pre-dialysis nursing care. A lack of time with patients was viewed as a barrier to providing adequate education, planning and developing structures and processes that ensure a quality service for pre-dialysis patients.**	*We educate them really, in a way that is not ideal. Our resources and time constraints mean we get usually one decent slot of time with the person and we bombard them with a lot of information* (pre-dialysis nurse, p. 30).
Finding 2: Cultural resources and issues (U, p. 30–31). **Having good access to cultural and other supports and an understanding of differing cultural views of health influences effective pre-dialysis nursing care. When easily available, culturally appropriate resources including interpreters, other cultural support personnel and written resources were**	*We have Māori liaison - kaitakawaenga, link to our service, so every family meeting we have we offer [this service] to the family….They do the mihi (formal welcome) and they do the karakia (prayer) before the meeting…If it's an elderly person who would like everything in a meeting translated then that's their role…They're not only support for the staff, the non-Māori staff, but also for the family*

considered an enabler of effective care and support for patients and families. By contrast, a lack of culturally diverse educational resources was an identified barrier to effective care.	*that are there. I think we do that extremely well. We also attend Treaty of Waitangi workshops* (pre-dialysis nurse, p. 30).
Finding 3: Inter-professional relationships (U, p. 31). **Good inter-professional relationships are an important influence on the delivery of effective pre-dialysis nursing care. Good interpersonal, interdisciplinary, inter-cultural and inter-organisational relationships were viewed as fundamental to the delivery of effective pre-dialysis nursing care.**	*You really need to spend time to foster the relationship with the iwi (tribal) providers, the private providers and the primary health care people like the GPs, and the GP's staff. So I call that a partnership and you've got to spend time to network with them* (pre-dialysis nurse, p. 31).
Finding 4: Advanced nursing practice issues (U, p.31–32). **Issues relating to advanced nursing practice influence the delivery of effective pre-dialysis nursing care. Pre-dialysis nurses viewed a lack of nursing autonomy to make key decisions and recommendations for the patients and a lack of support by nursing management and doctors to advance professionally and extend their scope of practice as a barrier to effective pre-dialysis nursing care. A lack of autonomy was viewed as a barrier to being able to advocate for patients, make the best decisions them and provide timely and effective care. It was viewed as stemming from a lack of infrastructure, and a lack of support among some doctors for nurse-led initiatives.**	*We lack autonomy to manage those patients earlier in my view…If we had our own clinics and prescribing rights we could…manage people in a different way and I think it could be a good thing….to be able to alter medication dose in a more timely way or perhaps prescribe new medications* (pre-dialysis nurse, p. 32). *There was a time when we brought up the option of nurse-led clinics and that was quickly squashed. We do try and bring up initiatives where we can be autonomous but, without the support of the physicians, it just doesn't go anywhere* (pre-dialysis nurse, p. 32).