# Feeling Queer:

Can a Primary Health Care approach mitigate health inequity experienced by homosexually active South Australian men?

by

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# Abstract

### Feeling Queer:

### Can a Primary Health Care approach mitigate health inequity experienced by homosexually active South Australian men?

### by Gary Rogers MB, BS, MGPPsych(Clinical)

Supervised by:

Professor Justin Beilby, Professor Deborah Turnbull,

(and formerly by Professor David Wilkinson)

Health inequity refers to differences in health status between populations (health inequalities) that are unnecessary and avoidable and, additionally, are considered unfair or unjust.

The history of the concept is reviewed and the mechanisms by which inequity affects health surveyed, with a focus on multi-level models of health production. The origins and development of the Primary Health Care approach is then considered with an emphasis on the Australian setting and on HIV/AIDS policy.

The construct of homosexuality is then explored and concepts of sexual attraction, 'orientation', identity and behaviour differentiated. What is known about the health characteristics of homosexually active men in the First World is then surveyed by means of a systematic literature review. It is concluded that there is evidence that they are affected by substantial health inequality in a range of areas including mortality, suicidality, depressive disorders, anxiety disorders, report of childhood sexual abuse and problematic substance use. Few of these inequalities have been confirmed in the Australian context, however, and almost none have been confirmed specifically in South Australia.

The background to the development of a Primary Health Care programme focused on homosexually active men, is then described. The baseline health characteristics of the programme's cohort of 542 homosexually active South Australian men (including their sexual behaviour in the context of HIV transmission) are described and compared with other samples of men to identify inequalities. It is concluded that men in the cohort were subject to health inequality in a wide range of health parameters including mortality, suicidality, sexually transmitted infections, depressive and anxiety disorders, levels of substance use and self-rated health on the short-form 36 (sf36) instrument.

The relationships between these characteristics and factors indicative of disadvantage and victimisation are then explored. It is concluded that many of the health inequalities identified were related to sociohistorical factors such as emotional withdrawal by one's father, low income, unemployment, reduced educational attainment, and recent experience of violence and abuse from strangers. It is argued that some of these factors can be considered to be examples of unfairness and injustice and that, as a consequence, at least some of the health inequality experienced by this population is also health inequity.

The elements of the Primary Health Care programme devised to meet the needs of homosexually active men is described and the trajectory of health characteristics of its participants over three time points is examined.

210 homosexually active men had reached Second Review, an average of thirty-six months after enrolment, by the time of analysis. Among this group, significant sustained improvement in a range of health outcomes, including prevalence of depressive disorders, sf36 scores and rate of recent suicidal ideation, is reported in association with involvement in the programme.

Participant's subjective satisfaction with the programme is then described and their beliefs about the causes of their improved health explored using a qualitative methodology. It is concluded that the programme had largely met the needs of participants and they believed that it had been responsible for their improved health.

Limitations of the study are considered and discussed. Limitations of the investigation to identify health inequality include questions of external validity arising from the absence of a perfect comparator group and concerns with construct validity related to the possibility of geographical and cultural variation in definitions of 'homosexually active men'. In the investigation to determine the extent to which health inequalities were also examples of inequity, issues of conclusion validity are discussed particularly in relation to multiple comparisons and the balance between Type I and Type II errors.

In the evaluation of the impact of the Primary Health Care programme, there are concerns about internal validity resulting from the absence of randomisation and an uncontrolled design. The components of this issue are discussed and some support for internal validity is found in the reported subjective beliefs of participants about the cause of their health improvement and the outcomes of critical reflection by the programme team.

The implications of the findings for policy, practice and further research are explored. It is argued that the health inequity experienced by people of sexual diversity will require profound social change for complete resolution. In the meantime, however, focused Primary Health Care with a community of sexual diversity has the potential to mitigate the health inequity its members experience and to help them to survive and function while they wait for a fairer and kinder society.

# Candidate's statement

This work contains no material which has been accepted for the award of any other degree or diploma 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.

I give consent to this copy of my thesis, when deposited in the University Library, being available for loan and photocopying.

Date: \_\_\_\_\_ 1<sup>st</sup> May, 2006

Gary Rogers

# Acknowledgements

This thesis was written, and the research to which it refers was conducted, on the land of the Kaurna people.

The thesis is informed by data collected in the course of the operation of a coordinated Primary Health Care service focussed on homosexually-active men in South Australia, between 1998 and 2003.

The service, which is now known as The Care and Prevention Programme, began operating at the start of 1998 as a project of the Adelaide Central and Eastern Division of General Practice funded by the (then) Commonwealth Department of Health and Family Services. In 2000 it was transferred to the Department of General Practice at the University of Adelaide and has been funded since that year by what is now the South Australian Department of Health. Small additional grants have been received from several pharmaceutical companies to assist with the provision of extended allied health services to participants.

The author conceived the Programme in consultation with members of the communities it serves, and has managed it since it began.

He devised its protocols, questionnaires and database and has undertaken all of the data analysis.

He is indebted to the participants in the Care and Prevention Programme for their inspiration, patience and generosity.

He also expresses deepest thanks to the other members of the Programme team for their assistance with the gathering of data and provision of care, as well as their wise counsel and advice, namely:

Michael Curry B Nurs, MNursSc, RN Joy Oddy Sarah Makinson BM, BS, FRACGP Jo Thomas BM, BS, FRACGP, FRACP Jill Thompson BSocSci, GradDipCours, RN Adrian Booth BSc (Hons), MPsych Alison Martin BSc, MNutrDiet Cassandra Hood BSc, MNutrDiet Ian Jennings MB, BS, FRANZCP Nick Rieger MB, BS, FRACS

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Professor David Wilkinson co-supervised the author's candidature until his departure from Adelaide in 2004 and gratitude is expressed for his invaluable help in the early stages of the research project.

The author also wishes to thank Justin Lokhorst for his assistance and vigilance against a tendency to statistical heresy, and Dr Chris Barton for a discerning critical reading of the thesis.

The author's friend and colleague Ann Lawless was there to hold his hand when he ventured nervously into the social sciences as the thesis unfolded, and her support through countless vigorous discussions, an insightful critical reading and innumerable cups of tea is acknowledged with warm affection.

Finally, he expresses his deepest gratitude to Peter Hamilton whose love, care and support over fifteen years have been the inspiration for this work as well as the crucial factor in its completion.



# PART ONE <u>Context</u>: What do the terms in the question mean and what is known already?

# Methodological Note

The work that is reported in this thesis was conducted in the borderlands between health science and social history. It focused on a population of subjects whose lives and health may be profoundly influenced by the historical context in which they find themselves and the operation of social power. (Foucault, 1976/1998)

As a result, a range of different methodologies has been employed, where techniques from the humanities and social sciences have been married to more traditional biomedical and epidemiological approaches.

In places, like the second half of Chapter 3 for example (see page 152), methods such as the 'systematic literature review' that is now so prized in the medical tradition have been found wholly appropriate to the task. In others, like the remainder of Part One, the techniques of history and narrative have been needed to build a nuanced picture of how the three concepts that are invoked in the thesis title have developed and crystallised in the recent history of humankind, and of Australians in particular.

Since the work aims to explore the impact of social power on marginalised subjects, it of necessity critiques the current state of the world. It cannot, therefore, be wholly 'dispassionate' in the traditional 'scientific' sense and will inevitably appear at times to be 'taking a line' and perhaps to be lacking 'balance'. In this context, the question to be answered in evaluating the work may not be whether it is always (traditionally) 'scientific'. Rather, the reader might ask whether, in its departures from biomedical methods in an attempt to criticise and unsettle familiar assumptions, it has made its case through logical argument and reference to the 'principles' that remain at this point in human history, such as those discussed at the beginning of Chapter 1.

# Chapter 1: Health inequity

### Preamble

There are few statements of principle that have anything approaching general currency in the late modern world.

Among those few is The Universal Declaration of Human Rights, which was adopted by the United Nations General Assembly in 1948.(United Nations, 1948)

Although it has become somewhat more politically contested in Australia in the last decade, and appears to have been used by some more as a yardstick against which to judge other nations rather than our own, it is still unacceptable in most of the world to assert opposition to the notions of 'human rights' embodied in the Declaration.

The Universal Declaration of Human Rights was largely brought about by Eleanor Roosevelt, who was the first chair of United Nations Commission on Human Rights. On the occasion of the fiftieth anniversary of its adoption, representatives of the Franklin and Eleanor Roosevelt Institute recorded that Eleanor envisioned it as 'a declaration with enduring principles that would be perpetually recognized by all nations' and that she 'was a strong advocate of true universality'.(National Coordinating Committee for UDHR50, 1998, no page number [NPN])

They went on to assert that:

Eleanor Roosevelt's concern for humanity made her the driving force behind the Universal Declaration of Human Rights. Her leadership of the Commission on Human Rights led to the composition of a Declaration that has endured as a universally accepted standard of achievement for all nations. As our respect for and understanding of the Universal Declaration has grown, so too has our gratitude and admiration for this modest woman who passionately pursued what she imagined would become a cornerstone in the struggle for human rights and fundamental freedoms for everyone - everywhere.(National Coordinating Committee for UDHR50, 1998, NPN)

Eleanor Roosevelt was also, it has since become clear, a person of sexual diversity. There is no doubt that she had a thirty-year loving relationship with Lorena Hickok, a journalist of her own gender whom she is reported to have first met around 1930, and it is almost certain that their relationship was 'sexually as well as emotionally intimate'.(Gianoulis, 2004, NPN)

The Declaration's unproblematised use of masculine forms to encompass all of humanity sounds sexist to contemporary ears, after the discourses of Feminism in the intervening time. Aside from this element, however, its language resonates with a surprising immediacy fifty-four years after it was drafted.

Article 1 of the Declaration states that:

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.(United Nations, 1948, NPN)

It sets the tone for a document that is as much a charter of responsibilities for individuals and communities as it is a statement of personal freedoms.

Article 2 states (in part) that:

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status...(United Nations, 1948, NPN)

The phrase 'or other status' at the end of this part can certainly be read to include 'distinction' on the grounds of sexual identity or behaviour and, in the light of what we have learnt since, makes us wonder about whether it was included specifically for this purpose.

Article 3 goes on to assert that:

Everyone has the right to life, liberty and security of person[,]

and Article 7 specifically identifies a right to freedom from discrimination:

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.(United Nations, 1948, NPN)

The other Articles of the Declaration that underpin a discussion of equity and health are:

Article 12, which states that:

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks[,]

and the first sub-article of Article 25, which declares that:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.(United Nations, 1948, NPN)

Together, these statements of principle form a compelling framework for the just and ethical consideration of the health of humans, its promotion and maintenance.

The Declaration has in its genealogy earlier statements of principle such as the French Constitution, which commits the Republic of France to 'ensure the equality of all citizens before the law, without distinction of origin, race or religion'.

Although it is now rarely examined directly by health care workers and researchers, the Universal Declaration of Human Rights forms the foundations of a way of thinking and speaking that is central to current western health practice.

It was also the starting point for formal processes of the United Nations (UN) that have developed notions of health inequity, discussed in this Chapter, and Primary Health Care, discussed in Chapter 3.

### Introduction

This thesis will focus on the health status of homosexually active men in South Australia and examine the impact of a Primary Health Care programme that has been conducted in the City of Adelaide since 1998.

It will be argued that homosexually active men are subject to significant health inequity, and demonstrated that this inequity may be mitigated by the application of a Primary Health Care approach.

Part 1 will define the context of the present study. The concepts of health inequity (this chapter) and Primary Health Care (Chapter 2) will be delineated, their history explored and what is known about the health of homosexually active men will be critically examined (Chapter 3). Particular reference will be made to Australia, and especially South Australia, as the setting for the health care programme under examination. Then, in Chapter 4, the background to the establishment of the programme will be presented.

Part 2 will describe the baseline health characteristics of homosexually active men who enrolled in the programme and make comparison with other populations to delineate the extent to which they are subject to health inequality.

In Part 3 the correlates of their health inequality will be considered, to examine how it may have come about, whether it also constitutes health *inequity*, and its possible consequences in terms of behaviour that might increase the likelihood of further transmission of the Human Immunodeficiency Virus (HIV).

Part 4 will examine the programme as a Primary Health Care approach and chart the health outcomes of participants.

Part 5 will summarise, reflect on the limitations of the study, draw conclusions and consider their implications for future research and practice.

### 'Health'

It is difficult to begin this discussion without a working definition of 'health'. The word is used every day without close scrutiny by health care practitioners and researchers but its meaning has been surprisingly contested.

The Oxford English Dictionary notes 'health's etymological connections with 'whole' and includes two pertinent definitions:

1. a. Soundness of body; that condition in which its functions are duly and efficiently discharged.

2. a. By extension, The general condition of the body with respect to the efficient or inefficient discharge of functions: usually qualified as *good*, *bad*, *weak*, *delicate*, etc.(Simpson, 2005, NPN)

The Merriam-Webster Dictionary in one of its definitions extends the idea beyond just the body:

1 a : the condition of being sound in body, mind, or spirit; especially : freedom from physical disease or pain.(Mish, 2005, NPN)

The most widely used definition in recent times is that formulated for the Preamble to the Constitution of the World Health Organisation (WHO), which was ratified in 1946 and came into effect in the same year as the Universal Declaration of Human Rights, 1948. It characterises 'health' as:

a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.(World Health Organization, 1946, p 2)

It is worth noting that although it has stood unamended for half a century, this conception of health has been subject to recent criticism.

Some of this appears to focus on the word 'merely', which might be taken to imply that a state of 'health' is not achievable in the *presence* of 'disease or infirmity'. This concern relates to an understanding of health as an absolute characteristic – one that is either present or absent – rather than a relative one (like height). The argument has been forwarded in particular by people with disabilities, who assert convincingly that 'individuals can experience disabilities and also be healthy and well'.(Krahn, 2003, p 12)

At a 2003 conference, Krahn observed that health (and wellness) involve 'physical, emotional, social, spiritual and other factors that enable individuals to maximize their potential and to fully participate in their communities.'(Krahn, 2003, p 12) She went on to observe that she and her colleagues had:

come to think of health and wellness as relative — relative to one's expectations based on age, condition, previous experience, peers, and the like. Rather than thinking of "health" and "illness" as opposite and binary categories, we find it useful to consider a continuum of health and illness that individuals move along, enjoying relatively better health at some times in their lives than others. A person's unique circumstances, then, define their "optimal health".(Krahn, 2003, p 13)

The implications of the current WHO wording for people with disabilities are not trivial and may prompt a revision in the future. It is also clear that the notion of health as a relative quality is logically implicit to any consideration of health relativities between groups.

Despite the fact that it was originally adopted by 61 nations, the current WHO definition is also open to criticism that it is distinctly western in its perspective and pays little heed to conceptions of health in other cultures. This issue will be felt most keenly by those peoples whose lands have been colonised by Western powers.

An interesting definition that begins to overcome this deficiency was developed by *Movimenta Sem Terra* (the Movement of Landless Rural Workers) in Brazil, and is quoted by Young:

[H]ealth is how and where you live, what you eat, and how you make a living. It is feeling well physically, being mentally at peace, living in a family setting where there is respect, affection, and equality among all, respecting nature, and living in a society in which justice and equality go hand in hand.(Young, 2003, p 47)

This form of words is interesting for its similarities to, as well as its differences from the WHO definition.

To accord with convention, the current WHO definition will generally be adopted for this discussion but the qualifications considered need also to be borne in mind.

### Health inequality

The WHO considers health inequalities to be 'differences in health status or in the distribution of health determinants between different population groups'. (Barnes, no date [ND], NPN)

The notion that the health status of individuals within a human population may be patterned in relation to social and behavioural factors is not new.

### History

The idea was there in a primordial form in the Hippocratic view of health. Writing about 400 years Before the Common Era (BCE), Hippocrates exhorted the physician investigating the health of people in a particular area to consider:

the mode in which the inhabitants live, and what are their pursuits, whether they are fond of drinking and eating to excess, and given to indolence, or are fond of exercise and labor, and not given to excess in eating and drinking, (Hippocrates, 400 BCE, p 1)

and referred to non-Greek societies where

men are not their own masters nor independent, but are the slaves of others [and] the dangers are not equally shared, since they must serve as soldiers, perhaps endure fatigue, and die for their masters, far from their children, their wives, and other friends; and whatever noble and manly actions they may perform lead only to the aggrandizement of their masters, whilst the fruits that they reap are dangers and death.(Hippocrates, 400 BCE, p 5)

The Roman orator Cicero, speaking in the First Century BCE, is said to have observed that:

a careful physician . . . before he attempts to administer a remedy to his patient, must investigate not only the malady of the man he wishes to cure, but also his habits when in health, and his physical constitution.(Cicero, ND, NPN)

It was not until 1567 in the Common Era (CE), however, that the first Western observation of health patterning was documented. In this year the alchemist Paracelsus is said to have noted unusually high rates of particular symptoms in miners and that they 'arose in different ways depending on each miner's degree of exposure and the kind of mining he did'.(Krieger, 2001b, p xxvii)

Then in 1662 CE, John Gaunt is reported to have counted deaths in county parishes in England and observed a sociogeographical patterning of mortality (Gaunt J, cited in Berkman and Kawachi (Berkman *et al.*, 2000)).

By the Nineteenth Century the so-called public health movements were underway in France (La Berge, 1984), Britain (Szreter, 1991) and the United States (Rosenberg *et al.*, 1968) among other places in the western world. Among their foci was 'the increased risk of disease among the poor'.(Berkman *et al.*, 2000, p 3) Not surprisingly, the attention of most workers was directed toward intervening to improve the health of people who were disadvantaged, through efforts to develop housing, water supply, sanitation and nutrition, rather than the study of health inequality as a phenomenon.

In Britain, Edwin Chadwick was the exception when he reported, in 1842, the results of life expectancy studies in multiple areas. Chadwick identified shorter life expectancy for 'labourers and artisans' than 'farmers and tradesmen', who in turn had shorter life expectancies than 'gentry and professionals', in every geographical area.(Chadwick, 1842/1965)

The Nineteenth Century was also the principal period in which the indigenous peoples and societies of much of the world were invaded and disrupted by colonising powers, with extraordinary impacts on their lives and health.

During the Twentieth Century the health of people in Western, and many colonised, countries appeared to improve steadily. For example, the average life expectancy for a male South Australian at birth rose from 53.0 years in 1900 to 76.6 years in 2000.(Australian Bureau of Statistics, 2004a) It seemed likely that the technological and practical advances of medicine and public health would deliver high levels of health for all humans.

The loudest warning that this rosy expectation was not to be fulfilled came in 1980 with the publication in Britain of what has become known as the Black Report after its principle author, Sir Douglas Black.(Black *et al.*, 1988)

#### The 'Black Report'

Originally written as the *Report of the Working Group on Inequalities in Health*, this study was commissioned by the British Labour government in 1977 in response to increasing concern about an apparent differential in mortality between the 'social classes' and a failure of British infant mortality rates to fall in accord with some other countries. As Townsend and his fellow editors observe in their introduction to the 1988 reprinting of the *Report*, 'among the countries of the world having the lowest infant mortality rate Britain ranked eighth in 1960 but had slipped to fifteenth by 1978'.(Black *et al.*, 1988, pp 1-2)

The Working Group appraised all of the available data on the health of Britons and by the time it reported in April 1980, there had been a change of government in the United Kingdom. The new Conservative Secretary of State, Patrick Jenkin, appears to have tried to minimise the public's attention to the Group's findings. Townsend and colleagues document that the *Report* was not properly printed but rather produced only as a run of 260 duplicated copies. It was released on a public holiday and the Secretary included a foreword of his own, which observed (in part) that:

the Group has reached the view that the causes of health inequalities are so deep-rooted that only a major and wide-ranging programme of public expenditure is capable of altering the pattern. I must make it clear that additional expenditure on the scale which could result from the report's recommendations – the amount involved would be upwards of £2 billion a year – is quite unrealistic in present or any foreseeable economic circumstances ... I cannot, therefore, endorse the Group's recommendations.(Black *et al.*, 1988, p 31)

What was so unpalatable for the new government was the *Report's* finding that the state of health inequality in Britain during the 1970s was so great that, for example, 'men and women in occupational class V (the 'lowest') had a two-and-a-half times greater chance of dying before reaching retirement age than their professional counterparts in occupational class I (the 'highest')' and '[a]t birth and during the first month of life the risk of death in families of unskilled workers [was] double that of professional families.'(Black *et al.*, 1988, p 44)

On this basis, Black's team went on to make fifteen practical but radical recommendations ranging from an immediate increase of child benefit to  $\pounds$ 5.70 per week, and the provision of free meals in schools, to the introduction of a 'comprehensive disablement allowance'.

Despite the Secretary of State's apparent efforts to 'bury' it, the British press did take what Townsend and colleagues described as 'a keen interest in the manner of the appearance of the report and its substance',[Townsend, 1988 #110\, p 3] and there followed critical editorial comment in the British Medical (BMJ, 1980a;, 1980b;, 1980c) and the Lancet (Lancet, 1980).

As Townsend's group went on to demonstrate, though, although the British government was forced to respond further, it did so by criticising the report and misunderstanding the link it made between health outcomes and social factors outside of the direct provision of health care. Patrick Jenkin argued in criticising the report that there was no evidence that the poor were missing out as they used health services at the same rate or higher than people of 'higher' social class.

Given that the Black Report showed much higher rates of morbidity among poorer people, Jenkin's observation is neither surprising nor relevant. It is to be expected that people with poorer health will find the need to use health services more. Indeed, what *was* surprising was that they were not using health services *much* more. Further, he argued that a long period of increasing expenditure on the National Health Service had failed to improve the population's health, which was precisely the point that Black and colleagues were making in their call for expenditure in other areas.(Black *et al.*, 1988)

There was ultimately little action on the Black Report under the Thatcher government in the United Kingdom in the eighties. A follow up report *The Health Divide,* published in 1988, found that very little had changed with regard to health inequality in Britain between the 1970s and the 1980s.(Whitehead, 1988)

More recent work at Britain's Townsend Centre – which is named for a member of Black's original Working Group, Professor Peter Townsend – argues that there was no action either under the Major Conservative government in the 1990s and highlights the further widening of health inequality in this period.(Shaw *et al.*, 2001) They cite Hattersley who reports that the gap in life expectancy in Britain between men doing unskilled manual jobs and men in professional occupations widened from 5.5 years in the early 1970s to 9.5 years by the mid 1990s.(Hattersley, 1999)

The Townsend group go on to criticise the Blair Labour government, which came to power in 1997, for being long on rhetoric about health inequality but short on action to tackle it. They point out that the government failed to set targets for reducing health differentials in its first four years of office and that health inequality in Britain appears to have worsened further during this period.(Shaw *et al.*, 2001)

From a contemporary standpoint, there are valid criticisms that can be levelled at the Black Report, and indeed much of the health inequalities literature from the United Kingdom. Black's conclusions hinge on mapping measures of health outcome such as mortality, infant mortality or prevalence of particular conditions against measures of 'social class'.

Social class is quite a contested descriptor and the Black Report's authors themselves acknowledge that although 'ranking occupations according to their social status or prestige' had been the traditional way to determine social class:

a variety of other factors may be said to play a part in determining class: income, wealth, type of housing tenure, education, style of consumption, mode of behaviour, social origins and family and local connections.(Black *et al.*, 1988, p 39)

They argued for a shift away from focus on the 'prestige' of occupations and suggested that:

every effort should be made to make [the] classification in the rankings of occupations as objective as possible, by taking into account current and lifetime earnings, fringe benefits, security, working conditions and amenities.(Black *et al.*, 1988, p 40)

They suggested the use of the term 'occupational class' rather than 'social class' where this framework was adopted. This is open to the obvious criticism that it fails to include some of the most privileged people in a society may not need to have an occupation at all since they can sustain themselves with inherited or accumulated wealth. Under an occupationally-based classification such people will either be misclassified or will be absent from the analysis altogether, despite their importance as an 'extreme' in the spectrum of privilege. Similarly, the classification appears to assume full employment of those who are in need of work. This has seldom been the case in Western countries in modern times and some of the most disadvantaged people in a community may be those who are unable to find work. This group would also be missing or misclassified under a purely occupational system.

Perhaps the most important concern about the study for the purposes of this thesis, however, is that it was focussed on the notion of a conventional heterosexual family unit and classified all members of such a unit according to the occupation of the male 'head of the household'. Unmarried women were excluded from some of the tables and graphs in the Black Report altogether. In others, married women were classified according to the occupation of their husband (even if they were working outside of the home themselves) while only single women were classified according to their own occupations.

Other domestic structures such as single parent families, non-married heterosexual cohabitation and same sex relationships (with or without children) do not appear to have been able to be captured at all by the system that was employed. While such structures are likely to have been less common in the 1970s than now, there is no doubt that they did exist and their exclusion from the analysis is a significant flaw.

Further, the validity of the very construct of social classes, which Black and colleagues saw as:

segments of the population sharing broadly similar types and levels of resources, with broadly similar styles of living and (for some sociologists) some shared perception of their collective condition[,](Black *et al.*, 1988, p 39)

has itself been called into question in recent times in the sociological literature. Pakulski and Waters, for example, have argued that:

[c]lass analysis de-emphasises gender and racial inequality, understates the exploitative character of authority relations by denying their autonomy, and glosses over the increasingly salient cleavages underlying the libertarian new politics. The best of these [class] analyses are becoming irrelevant; the worst forms are misleading.(Pakulski *et al.*, 1996, p 684)

Notions of social class have a long history in Western thought, however, and – at least it relates to income and education level – 'class' remains a useful construct in the practical study of health inequality.<sup>\*</sup>

Despite the criticisms, the historical significance of the Black Report remains. The magnitude of the difference in mortality and morbidity that Black and colleagues documented, and their observation that such differences were widening rather than narrowing as 'medical science' advanced, had a profound effect on the thinking of health care and social researchers in the Western world.

The Black Report was followed a year later by Rose and Marmot's report of the social gradient in cardiac mortality among British Civil Servants in the prospective Whitehall Study.(Rose *et al.*, 1981) These landmark publications started the development of a framework for the study of health inequality that has the potential, where there is political will, to improve the health of disadvantaged people markedly.

<sup>\*</sup> Lynch and Kaplan have argued for the use of the alternative term 'socioeconomic position' to mean:

The social and economic factors that influence what positions(s) individuals and groups hold within the structure of society, i.e., what social and economic factors are the best indicators of location in the social structure that may have influences on health. (Lynch *et al.*, 2000, p 14)

This definition addresses some of Pakulski's concerns about the disregard of gender and racial inequalities (and for that matter inequalities related to sexual identity or any other social characteristic) in the term 'class' but does so by invoking a kind of circularity. It says, essentially, that 'socioeconomic position' as a determinant of health comprises all of the social factors that determine health. It thus becomes inclusive but meaningless.

#### **Geographical inequality**

The British studies of health inequality mentioned so far, from Chadwick to *The Health Divide*, compared health characteristics with the allocated 'social class' of individuals within a specified population. Much of the other work in Britain and almost all of the Australian literature have made use of the fact that there is also a geographical distribution of social advantage. These studies use rankings of the 'average' socioeconomic status of people in a particular geographical region as a surrogate for measuring advantage at an individual level.

Thus, it has been determined that, for example, people born in a the City of Mitcham (in the Eastern suburbs of Adelaide) between 1997 and 2000 had an estimated average life expectancy of 82.1 years, while for people born in the City of Playford (in the Northern suburbs of Adelaide) the life expectancy was 77.7 years.(Hetzel *et al.*, 2004)

It is also known from Census data that people in Playford have, on average, relatively less skilled occupations, higher rates of unemployment, lower incomes and lower educational attainment than people in Mitcham.(Hetzel *et al.*, 2004) These characteristics seem to encompass most of the elements of Black's definition of social class (see page 34).

Thus, when the health characteristics of people who live in Mitcham and people who live in Playford are compared and differences are found, the same kinds of inequality that Black identified are taken to be present in the population of Adelaide.

In this approach, residence in a geographical region (such as a Statistical Local Area as determined by the Australian Bureau of Statistics) is used as a convenient proxy for individual social characteristics.
As well as being expedient, it has been argued that investigation of geographic area of residence as a determinant of health outcome may also have an *advantage* over individually-based measures of social variables. This is because it assesses other health-determining effects of a social milieu that would be missed by measuring the social characteristic on an individual basis. Lynch and Kaplan give the example that:

the percentage of unemployment in an area not only indicates something about the individuals who live there (the composition of the area); it may also provide other information about the area that conditions the health risks of all those who live in the area – not just the unemployed individuals: that is, the area characteristics may have a contextual effect on individual health.(Lynch *et al.*, 2000, p 29)

Gakidou and King, on the other hand have argued that while measuring inequality in health outcomes between groups (including geographically-defined groups) is important, an understanding of what they call 'total health inequality' also requires determination of the distribution of the outcome *within* the groups being compared.(Gakidou *et al.*, 2002)

They point out, for example, that while the two African countries Benin and Central African Republic have almost identical rates of child mortality before age two (13% and 12% respectively) the countries differ markedly in the way that this mortality is distributed in their societies. In Central African Republic there is a marked economic inequality *within* the country so that 25% of children have a less than 3% chance of dying before age two while in Benin there is a more even distribution and only 4% of children have a less than 3% chance of dying before the allows that 1% of children have a greater than 40% chance of infant death, while in Central African Republic, more than 4% of children have this level of risk.

While both countries have unacceptably high rates of infant death, it can be seen that quite different approaches would be required to address the issue in the two settings. In Benin, a whole of population approach would be required to effect major change, while in Central African Republic much could be gained from concentrating efforts on the portion of the population that is worst off.

Gakidou and King argue that this problem is not just a function of using large groups such as countries as the basis of measurement but is inherent to groupbased measures of inequality. They argue that only with a measure of individual variation added to between-group analysis can:

public health policy ... be targeted at reducing inequalities across individuals, in addition to the existing goal of reducing disparities in average health status across countries and groups in society.(Gakidou *et al.*, 2002, p 3)

Asada and Hedemann on the other hand, in a critique of the WHOs *World Health Report 2000,* which adopted an approach similar to that advocated by Gakidou and King, expressed concern that measuring the distribution of health outcomes across individuals in a population may actually serve to *mask* systematic inequalities.(Asada *et al.*, 2002) They argue that a narrow spread of a health outcome in a geographical area does not preclude the possibility of one cultural group, for example, occupying the 'top' of that (albeit narrow) curve and another occupying the 'bottom'.

There has been much geographically-oriented health inequality research in Australia in the last few years. In 2004, for example, the South Australian Department of Health released a report that mapped a variety of health outcomes, as well as a range of social variables, to Statistical Local Areas.(Hetzel *et al.*, 2004) The report revealed a pattern of health inequality across the state of South Australia that closely followed the geographical distribution of socioeconomic advantage.

What the report's geographically-based methodology did not allow it to determine, however, is the presence of groups within each area, and across the South Australia generally, that are systematically disadvantaged independent of their members' geographical location or personal economic circumstances.

Indigenous Australians are the most obvious group whose particular disadvantage is invisible in geographically-based studies and the South Australian report relied on other studies to document their health status compared with that of non-Indigenous people.

Other groups who may be systematically disadvantaged, such as people of sexual diversity, are not identified in geographical surveys and to date no attempt has been made in this jurisdiction to determine their health status by other methods. Despite purporting to be a comprehensive report that 'explains what the social determinants of health are', the South Australian document fails to mention people of sexual diversity anywhere in its 94 pages.

The existence of 'gay ghettos' might be thought to enable the use of geographical inequality data for examination of the health status of people of sexual diversity. While this might be partly feasible in Sydney or Melbourne, there appears to be no particular geographical concentration of lesbian, gay, bisexual, transgender and intersex (LGBTI) people in any part of South Australia. It is also crucially important to realise that the people of sexual diversity who are able to reside in gay ghettos, where they exist, may well be those who are relatively advantaged, since they need to have had the resources and information required to move to these areas. LGBTI people who are not able to move to gay ghettos may well experience even greater health disadvantage.

# Health inequity

The term 'health inequity' (as opposed to 'inequality') appears to have been coined in 1992 by Margaret Whitehead, author of the *Health Divide* report mentioned above, who was, at the time she introduced the term, in the World Health Organisation's European Office.(Whitehead, 1992) Whitehead differentiated 'health inequity' from 'health inequality' by noting that:

the term "inequity" has a moral and ethical dimension. It refers to differences [in health that] are *unnecessary* and *avoidable* but, in addition, are also considered *unfair* and *unjust*.(Whitehead, 1992, p 431, original emphasis)

Earlier authors had considered the ideas that Whitehead sought to encompass with the term, however. Black's group, in their 1980 report, distinguished between 'differences' and 'inequalities' by applying a similar moral appraisal:

The distribution of health or ill-health among and between populations has for many years expressed most forcefully in terms of ideas on 'inequality'. These ideas are not just 'differences'. There may be differences between species, races, the sexes and people of different age, but the focus of interest is not so much natural physiological constitution or process as outcomes which have been socially or economically determined ... For some the concept of inequality also carries a moral reinforcement, as a fact which is undesirable or avoidable.(Black *et al.*, 1988, pp 38-39)

In her original 1992 paper, Whitehead explored the elements of health inequity further by discussing seven potential determinants of health differentials, namely:

- 1. Natural, biological variation
- 2. Health-damaging behavior if freely chosen, such as participation in certain sports and pastimes.
- 3. The transient health advantage of one group over another when that group is first to adopt a health-promoting behavior (as long as other groups have the means to catch up fairly soon).
- 4. Health-damaging behavior where the degree of choice of lifestyles is severely restricted.
- 5. Exposure to unhealthy, stressful living conditions.
- 6. Inadequate access to essential health and other public services.
- Natural selection or health-related social mobility, involving the tendency for sick people to move down the social scale. (Whitehead, 1992, p 432)

She suggested that:

health differences determined by factors falling into categories 1, 2 and 3 above would not normally be classified as *inequities* in health [while] [t]hose arising from categories 4, 5 and 6 would be considered by many to be avoidable and the resultant health differences to be unjust.(Whitehead, 1992, p 432)

For the seventh category, she noted that while the original ill health experienced by a person may have been unavoidable, 'the low income of sick people seems both preventable and unjust'.

Whitehead maintained that whether a person had *chosen* the circumstance that determined their ill health, or whether 'it was mainly out of their direct control', was important:

For example, through lack of resources, poorer social groups may have little choice but to live in unsafe and overcrowded housing, to take dangerous and dirty work, or to experience frequent bouts of unemployment. The higher rates of ill-health resulting from such environmental factors are clearly inequitable ... [but] for example, skiing injuries suffered more frequently by certain groups would not invoke the same sense of injustice, since the cause – skiing – is widely viewed as a voluntary activity chosen by those who accept ... the risks involved.(Whitehead, 1992, pp 432-433)

But, according to Whitehead, chosen health determinants may also be inequitable if choice has been restricted by social circumstances:

For example, a less nutritious diet may be chosen because of restrictions on income or inadequate food distribution networks, leading to a lack of fresh supplies in the shops. Less physical activity may be undertaken because of lack of leisure facilities or of income or time to make use of them.(Whitehead, 1992, p433)

Finally, she argues that unrestricted health-damaging choices may *still* be inequitable if they result from deliberate persuasion:

Promotion of health-damaging products may be targeted at certain groups in society, such as young working-class men and alcohol advertising or young women and tobacco promotion. This puts them under greater pressure than others to consume these products. (Whitehead, 1992, p433)

Whitehead summarises by suggesting that equity is really a matter of 'creating equal *opportunities* for health' (original emphasis) and proposes the following as a definition of health equity:

Equity in health implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that none should be disadvantaged from achieving this potential, if it can be avoided. (Whitehead, 1992, p 433)

As Whitehead observed, it is also vital to distinguish between equity of health status (the concept discussed so far) and equity in health *care*. Many people who experience socially-determined ill health are also disadvantaged in their ability to access the health services they require. This results from barriers such as the direct and indirect costs of care, inability to afford health insurance, language difficulties or a lack of culturally appropriate services, and uneven geographical distribution of providers combined with an inability to afford transport to them.

The observation that '[t]he availability of good medical [and other health] care tends to vary inversely with the need for it in the population served' was made by Welsh general practitioner Julian Hart in 1971, who famously dubbed the phenomenon 'the inverse care law'.(Hart, 1971)

Mooney, writing in 1996, distinguished two dimensions of health (and health care) equity, namely 'horizontal' and 'vertical'.(Mooney, 1996) Horizontal health equity is 'the equal treatment of equals' while vertical equity is 'unequal (but equitable) treatment of unequals' or as Bambas and Casas put it:

*horizontal equity* is the allocation of equal or equivalent resources for *equal need; vertical equity* is the allocation of different resources for *different levels of need*. (Bambas *et al.*, 2001, p 14, original emphasis)

Mooney demonstrated these ideas by imagining the slicing of a cake with equal sized portions available to two individuals (A & B) as an example of horizontal equity.(Mooney *et al.*, 1997) He then considered the same scenario where:

A is starving and B has just been dining at the Ritz[.] ... [E]ven if the process of allocation might still be deemed, according to certain values, to be fair, then in the wider community ... there may be a view that A should get more or even all of the cake.(Mooney *et al.*, 1997, p 80)

This view is a demonstration of vertical equity.

It is immediately evident that vertical equity is a more politically contested value than horizontal equity. The horizontal variety amounts to equality of opportunity and would be considered a core value by most Australians as 'a fair go'. Vertical equity calls for a redressing of historical unfairness and might be seen as undesirable 'social engineering' by some on the right of the political spectrum.

# How inequity influences health - multi-level models

There has been a great deal of research that has attempted to elucidate the mechanisms by which social factors exert their influence on health.

After Pasteur and Koch's work in the Nineteenth Century verified the Germ Theory of causation of infectious disease, early Twentieth Century health workers were faced with the question, as Krieger puts it, of 'why it is that not all people exposed to germs become infected and not all infected people develop disease'.(Krieger, 2001a, p 669)

This led to the development of notions that the development of disease resulted from the interaction between a causative agent, the host and the environment. This reasoning was later extended to include cancer and other illnesses as well as infectious diseases.

In the 1940s and 1950s, John Cassel was among the first to postulate that 'the social environment' was a major determinant of host susceptibility to disease. As Krieger notes in her 2001 review of this topic, after Cassel's work was published in the year he died (1976), 'research in psychosocial epidemiology blossom[ed]'. (Krieger, 2001a, p 669) Laboratory studies in the emerging fields of psychoneuroendocrinology and psychoneuroimmunology showed clear connections between psychosocial stress and bodily function, while George Engel refined his famous biopsychosocial model for understanding human health that remains central to the thinking of many clinicians today.(Engel, 1977)

The biological mechanisms involved have been well summarised by Brunner and Marmot, who outline the sympatho-adrenal and hypothalamic-pituitaryadrenal elements of the stress response.(Brunner *et al.*, 1999) They go on to consider the effects of *chronic* stress through a discussion of McEwen's 'allostatic load hypothesis'. In this model, 'allostasis' is seen as 'the ability to achieve stability through change' and focuses on the adaptation of an organism to environmental perturbations.(Brunner *et al.*, 1999, p 27)

Brunner and Marmot point out that the 'price of adaptation to external and internal stress may be wear and tear on the organism' and give the example of diabetes as a possible result of allostatic load on the physiology of blood glucose control. They go on to consider the effects of stress on haemostatic and immune functions and review the compelling evidence for these effects from human and animal studies.

As Krieger also points out, though, in parallel with these developments in understanding the biology of health inequity, there were also discourses developing in the humanities that are essential to a complete understanding of the phenomenon. She identifies an area of work she terms the 'Social production of disease/political economy of health' and argues that this 'second theoretical framework accordingly introduces agency to the "upstream-downstream" metaphors increasingly invoked in social epidemiology'.(Krieger, 2001a, p 670)

The 'upstream-downstream' idea is perhaps best demonstrated by the following story, whose origin is obscure, but is quoted here as told by Slavin:

Once upon a time, there was a town that had in it a playground located at the edge of the cliff. Every so often a child would fall off of the cliff and would be seriously injured. At last the town council decided that something should be done. After much discussion, however, the council was deadlocked. Some council members wanted to put a fence at the top of the cliff, but others wanted to put an ambulance at the bottom.(Slavin, 1995, NPN)

'Downstream' considerations focus on the end of the continuum of the production of health outcomes represented by the ambulance in the story. The ambulance prevents harm to the children by enabling rapid treatment of their injuries and thus the prevention of complications, death and disability. Another example of a relatively 'downstream' prevention intervention would be the treatment of hypercholesterolaemia with a statin drug to prevent cardiovascular disease.

'Upstream' deliberations consider interventions of the character of the proposed fence in the story. Equally, the council might have decided to finance the relocation of the playground to a less perilous site. In the case of cardiovascular disease an 'upstream' intervention might be subsidised provision of healthy food and exercise opportunities for people who are financially disadvantaged.

As McKinlay and Marceau point out, upstream and downstream understandings of the production of ill health rely on different philosophical underpinnings.(McKinlay *et al.*, 2000)

Downstream thinking results from an *individualist* perspective and a *mechanistic* view of health production.

Individualism is a 'social theory which advocates the free and independent action of the individual, as opposed to communistic methods of organization and state interference' according to the Oxford English Dictionary.(Simpson, 2005, NPN) This seems to be a curiously biased entry for a publication that would purport to be value-free. The phrase 'state interference' carries a particularly negative overtone. The following anonymous definition from the publicly-authored Wikipedia seems more balanced: 'a theoretical or practical emphasis on the individual, as opposed to, and possibly at the expense of, the group'.(Anonymous, 2004b, NPN)

According to McKinlay and Marceau, who note the predominance of both individualist and mechanistic approaches in the United States, the term 'mechanistic' in this context implies a focus on:

[d]isease states and on factors that predispose people to, are associated with, or increase the chances of entering into a disease state. This pathogenic view treats people as biopsychosocial and neurophysiologic systems, in which disease produces disequilibrium and dysfunction.(McKinlay *et al.*, 2000, p 26)<sup>\*</sup>

<sup>&</sup>lt;sup>\*</sup> This definition is interesting because its inclusion of the 'psychosocial' (as part of 'biopsychosocial') would seem to go beyond the definition of 'mechanistic' in the Oxford English Dictionary ('[o]f or relating to theories which explain phenomena in purely physical or deterministic terms') and imply a kind of holism.

McKinlay and Marceau go on to argue that upstream thinking results from a *collectivist* standpoint and an *holistic* view of health. By collectivism they say they mean a 'focus on *categories* (age, sex, social class, race/ethnicity) or *places and social positions in society* '(McKinlay *et al.*, 2000, p 26, original emphasis). However, they also seem to imply components of the Wikipedia definition of the term: 'a theoretical or practical emphasis on the group, as opposed to (and seen by many of its opponents to be at the expense of) the individual'(Anonymous, 2004a, NPN) and the Marxist elements evident in the Oxford English Dictionary definition: '[t]he socialistic theory of the collective ownership or control of all the means of production, and especially of the land, by the whole community or State, i.e. the people collectively, for the benefit of the people as a whole.'(Simpson, 2005, NPN)

The idea of holism in this context is characterised by Nijhuis and Van der Maesen, who described it as a view where:

Health is seen as an expression of the degree to which an individual is capable of achieving an existential equilibrium. This equilibrium is not static but continuously in motion. Pathological disturbances of the equilibrium must be interpreted from different angles,(Nijhuis *et al.*, 1994, p 2)

with the addition of elements of the Oxford English Dictionary definition of 'holistic medicine' which it sees as attempting 'to deal with the whole person and not merely with his or her physical condition'.(Simpson, 2005, NPN)

As Krieger points out, upstream orientations, based on collectivist and holistic foundations, look for structural and societal explanations of ill health, and arose in part 'as a critique of proliferating blame-the-victim "lifestyle" theories, which emphasize individuals' responsibility to "choose" so-called "healthy" lifestyles and to cope better with stress', without reference to social effects on the range of choices that could be made. (Krieger, 2001a, p 670)

Flowing from this approach, Krieger argues, is the conclusion that 'strategies for improving population health require a vision of social justice, backed up by active organizing to change unjust social and economic policies and norms'.(Krieger, 2001a, p 671)

But Krieger recognises that neither the biological investigation of the mechanisms of disease causation nor sociological investigation of the production of health are sufficient for a complete understanding of how the health of humans and their populations is determined. She, in common with others such as Susser,(Susser, 1999) argues for the use of what she calls 'multi-level frameworks integrating social and biological reasoning and history' to move the consideration of health determination from an "either/or" to a "both/and" logic'.(Krieger, 2001a 671)

A number of illustrative images have been proposed as metaphors for such a model but Krieger – who calls her model 'ecosocial theory' – favours what she describes as a:

visual fractal metaphor of an evolving bush of life intertwined at every scale, micro to macro, with the scaffolding of society that different core social groups daily reinforce or seek to alter.(Krieger, 2001a, p 671)

She choses fractal objects such as the plane generated by the famous Mandelbrot set (an object that reveals the same degree of complexity irrespective of the extent to which it is magnified) to emphasise that the model 'must be understood to exist at every level, subcellular to societal, repeating indefinitely'.(Krieger, 1994, p 896) A fractal image created with the software programme *Fractal eXtreme* is included here as a demonstration.(Dawson, 2003)



Figure 1: Fractal image

Ecosocial theory, in common with other attempts at the formation of multi-level models of health production, draws on the perspective of ecology, which Krieger describes as 'a science devoted to study of evolving interactions between living organisms and inanimate matter and energy over time and space'.(Krieger, 2001a, pp 671-672)

Her approach then incorporates recognition of social, political and economic processes that also shape epidemiological profiles, to provide a comprehensive picture of causality and determination.

While Krieger is at pains to point out that 'emerging ecologically inclined multilevel social epidemiological frameworks remain rather sketchy' and represent the 'bear beginnings of a mental map', she maintains that ecosocial theory 'fully embraces a social production of disease perspective while aiming to bring in a comparably rich biological and ecological analysis'.(Krieger, 2001a, p 672)

She proposes four ecosocial constructs that enable us to:

begin to elucidate population patterns of health, disease and well-being as biological expressions of social relations, and ... likewise begin to see how social relations influence our most basic understandings of biology and our social constructions of disease – thereby potentially generating new knowledge and new grounds for action.(Krieger, 2001a, p 672)

These constructs are:

**embodiment,** which refers to how humans 'literally incorporate, biologically, the material and social world in which we live, from conception to death' so that human biology cannot be understood without 'knowledge of history and individual and societal ways of living'

#### pathways of embodiment, that are structured both by:

'societal arrangements of power and property and contingent patterns of production, consumption, and reproduction', and

'constraints and possibilities of our biology, as shaped by our evolutionary history, our ecological context, and individual histories, that is, trajectories of biological and social development'

**cumulative interplay between exposure, susceptibility and resistance** with each factor in these pathways of embodiment seen to act at `multiple levels ... and in multiple domains ... in relations to relevant ecological niches, and manifested in processes at multiple scales of time and space;' and

**accountability and agency** 'expressed in pathways and knowledge about embodiment, in relation to institutions ... households and individuals, and also to accountability and agency of epidemiologists and other scientists for theories used and ignored to explain social inequalities in health'.(Krieger, 2001a, p 672)

Krieger proceeds, in her 2001 paper, to demonstrate the application of a multilevel model in the case of the preponderance of hypertension among African Americans. She makes evident the ways in which ecosocial theory can 'recast' what where purported to be 'racial' differences in biological function as 'mutable and embodied biological expressions of racism'. By highlighting accountability she shows that the model can move beyond simplistic psychosomatic notions of 'anger' and 'hostility' causing biological outcomes to reveal the social processes such as 'interpersonal and institutional discrimination' that engender these responses. She explains that the model's regard for the 'dynamic and cumulative interplay between exposure, susceptibility and resistance' provides insight beyond a focus on 'racial/ethnic disparities in socioeconomic position among adults to highlight discrimination within class strata plus ongoing biological impact of economic deprivation in early life'.(Krieger, 2001a, p 673)

Thus Krieger argues that:

more than simply adding 'biology' to 'social' analyses, or 'social factors' to 'biological' analyses, the ecosocial framework begins to envision a more systematic integrated approach capable of generating new hypotheses, rather than simply reinterpreting factors identified by one approach (e.g. biological) in terms of another (e.g. social).(Krieger, 2001a, p 673)

As the 'father' of British health inequality studies, Professor Michael Marmot, put it in a recent review:

The enterprise of understanding the social determinants of health entails an understanding of how society operates, an appreciation for the major causes of diseases under study, an understanding of psychological processes and how they may interact with relevant biological mechanisms and a readiness to learn from animal models.(Marmot, 2000, p 365)

Multi-level models appear to provide an appropriate framework for understanding the health impact of social phenomena that bear on the health of the homosexually active men in the present investigation.

## Social variables investigated to date

Since the Black Report's focus on social class as an indicator against which to judge health inequity, (Black *et al.*, 1988) a range of other variables have been the subject of investigation and have demonstrated a relationship with a gradient of health outcomes.

The vast majority of this work has focused on elements that might be seen as refinements to, or subsets or close correlates of, the social class or social position constructs (see page 35).

#### Socio-economic position-related variables

So, for example, a variety of occupational scales have been devised that have sought to refine 'status' based stratification such as the British Registrar General's classification (used by Black) and the US Census classification used in North America. Nam and Powers developed an occupational scale based on the average income and education level of particular occupations in the United States from Census data, (Nam *et al.*, 1983) while Wright added information about the supervision of others and control over decision-making in particular occupations.(Wright, 1996)

Bartley found health correlates with unemployment, (Bartley, 1994) while many authors have looked at self-reported income either directly (eg Backlund and colleagues, 1996) or as a proportion of an official poverty level (eg Lynch and colleagues, 1997). A few researchers such as Smith and Kington (1997), have looked at wealth as well as income, as a measure that would be expected to influence people's sense of security and would also account for the paradox of very wealthy people and older people who have undergone planned retirement sometimes appearing to be 'unemployed' in occupation-based scales.

Several studies have examined educational attainment as a health correlate. Elo and Preston, in 1996, identified substantial health differentials on the basis of years of school attended among US citizens, even when controlling for income, marital status and current place of residence. (Elo *et al.*, 1996))

Some workers have also attempted to derive meaningful socioeconomic scales applicable to non-Western cultures, such as Dye and Lee who found that in Kashmiri villages the number of livestock a person owned was a meaningful indicator of socioeconomic position.(Dye *et al.*, 1994)

For studies using the geographically-based methods of health inequity research discussed on page 36, a variety of composite measures of social position in a region have been devised. Armstrong and Castorina, for example, developed a measure of the 'occupational structure' of counties in Washington State in the USA, and found a clear correlation between the proportion of people with non-white-collar jobs in a county and the mortality from coronary disease.(Armstrong *et al.*, 1998, p 370) The measure was also associated with reduced access to a variety of health and community services (health *care* inequity).(Armstrong *et al.*, 1998)

Lynch and colleagues used 1990 US Census data to derive a descriptor of the economic structure of geographical areas that included measures not only of average income but also of income inequality in the region.(Lynch *et al.*, 1998) They found that areas with the lowest average income and the highest income inequality had an excess mortality of 140 deaths per hundred thousand per year. Lynch's group pointed out that this represented a level equivalent to 'the combined loss of life from lung cancer, diabetes, motor vehicle crashes, HIV infection, suicide and homicide in 1995' and suggested that as a result 'public and private sector initiatives to reduce economic inequalities should be a high priority' for US society.(Lynch *et al.*, 1998 , 1079) Meanwhile, Mayer and Jencks derived a scale for what they called 'material hardship' related to ability to purchase food, quality of housing, access to medical care, ability to pay utilities bills and social crowding.(Mayer *et al.*, 1989, p 88)

In the United Kingdom, several composite scores have been developed including the Townsend Index of Deprivation, (Townsend *et al.*, 1988) which combines markers such as unemployment patterns in an area, percentage of households without a motor vehicle, the extent of overcrowding and the distribution of different types of housing tenure.

The Carstairs Index, devised in Scotland, uses similar variables but also includes the proportion of people classified in the two 'lowest' social classes as determined by the Registrar General's classification,(Carstairs *et al.*, 1991) while Jarman's Underprivileged Area Score includes a range of other factors such as the proportion of lone pensioner households, the number of single parent families and measures of geographical mobility for residents in an area.(Jarman, 1983) Eames and colleagues used all three of these measures and demonstrated that each correlated strongly with all-cause mortality, coronary heart disease rates and smoking-related disease rates in geographical areas.

In Australia as well, there has been a particular focus on composite measures of social disadvantage that has been related to an evolving policy discourse on 'social exclusion'.(Saunders, 2003) The Australian Bureau of Statistics (ABS) has developed several 'Socio Economic Indexes for Areas' and has reported these on data from the last two censuses. The Index of Relative Socio-Economic Disadvantage (IRSD), for example, is based on education, income and occupation but these data are augmented by what Trewin calls 'second and third level variables' like wealth, living conditions, access to services and the proportion of Indigenous people living in the area.(Trewin, 2001, p 1) The ABS itself has used this index against which to map a number of health outcomes,(Australian Bureau of Statistics, 2004c) and several other agencies have used the index to investigate health inequities. The report *Inequality in South Australia*, mentioned earlier (see page 38) uses this approach to map the IRSD as well as a range of health outcomes to Statistical Local Areas.(Hetzel *et al.*, 2004)

A smaller number of studies have looked at markers of extreme socioeconomic disadvantage such as homelessness. A 1994 study led by Bines compared morbidity rates in people who were 'sleeping rough' with those of average Britons of the same age and sex using data from the British Household Panel Survey.(Bines, 1994, p 1) The matching was important since the homeless people were, on average, younger than people in the general community and thus would otherwise have been expected to have had *better* health.

Bines found rates of chest and breathing symptoms among homeless people that were more than three times the comparable rate in the broad community and rates of 'fits or loss of consciousness' that were over twenty times those in Britain generally.(Bines, 1994, p 4)

In the United States, D'Amore and colleagues reported in 2001 a case control study of 252 homeless compared with 88 non-homeless people attending an emergency department.(D'Amore *et al.*, 2001) They showed 3.8 times greater Relative Risk (RR) of HIV infection, a 2.5 times greater RR of tuberculosis, a 13.4 RR for self-reported 'depression' and a RR of 24 for self-reported 'alcoholism' among homeless people compared with non-homeless attendees. All of these differences were reported to be statistically significant at the P<0.01 level.

In Australia, Kermode and colleagues assessed the health of 384 homeless people in Melbourne in the mid 1990s.(Kermode *et al.*, 1998) They reported very high rates of a range of health problems in this group but did not include a control group or undertake comparisons with population rates, and so did not confirm health inequity *per se*.

#### **Other variables**

Socioeconomic differences have clearly been the focus of the majority of the research on health inequity. More recently, however, a smaller number of investigators have started to chart health inequity based on other characteristics that have social significance. Many of these, such as 'racial' or 'ethnic' grouping in some societies, Aboriginality in colonised countries and gender, exert their effect on health at least in part through associated socioeconomic disadvantage. For most of them, however, effects can be observed that remain when controlling for economic markers and point to social effects on health beyond just financial ones. As Krieger points out in her example of hypertension in African Americans (see page 49), from a multilevel standpoint we can expect economic and non-economic influences to wind around each other and interact to produce the health profiles of disadvantaged groups.

#### 'Race', 'ethnicity' and Aboriginality

This complex intertwining can be seen in the results of Otten and colleagues, for example, who in 1990 analysed follow up data from 10,783 participants in the US National Health and Nutrition Examination Survey to determine the 'causes' of 'excess' cardiovascular mortality among black Americans.(Otten *et al.*, 1990, p 845) They concluded that 31% of the cardiac deaths among black adults were attributable to 'known risk factors' such as smoking, high blood pressure, high cholesterol, alcohol intake, obesity, and diabetes; 38% could be attributed to economic disadvantage; while 31% remained 'unaccounted for'. As ecosocial theory would predict, some of the 'known risk factors' were also associated with financial disadvantage in a complex pattern of causality. Almost a third of the risk of cardiac mortality in this group, however, appeared to be related to other factors associated with identifying as 'black', chief among which seem likely to be the effects of discrimination and vilification.

In Britain, Nazroo has also looked at adjusting the Relative Risks of various health outcomes among 'ethnic' groups for measures of social class in data from the 1991 Fourth National Survey of Ethnic Minorities.(Nazroo, 1999) He found significantly higher rates of reporting only fair or poor health and higher rates of diabetes among Caribbean-identified and Pakistani- or Bangladeshiidentified Britons than the British community generally. He points out that the conventional British measures of social class were less meaningful among migrants to the country and noted that adjustment for 'traditional measures of occupational class' made 'no real difference to the relative risks', but:

adjusting for [a] more sensitive standard of living index ... (which took into account housing problems, number of consumer durables owned, and number of cars owned) ... gives a large reduction in relative risk for [almost] all of the ethnic minority groups.(Nazroo, 1999)

Regardless of these clear reductions, however, substantial differentials in health remained in these groups after adjustment for standard of living. Pakistaniand Bangladeshi-identified British respondents had a 4.9 times Relative Risk of diabetes (standardised for age and gender) on direct comparison while controlling for standard of living lowered this to a RR of 4.1.

In Australia, there has been a substantial amount of work on the health disadvantage of people who identify as Indigenous, compared with non-Indigenous Australians. Thomson and co-workers at Edith Cowan University have recently completed a detailed *Overview of Indigenous Health*, which summarises the research findings well.(Thomson *et al.*, 2004) This report documents substantial health inequalities experienced by Indigenous people in Australia generally or in particular Australian states, some of which are summarised in Table 1 on page 56.

Condition	Jurisdiction	Rate comparison
Life expectancy	Australia	For males: 56 yrs vs 77 yrs for NI For females: 63 yrs vs 82 for NI
Low birth weight	Australia	13% vs 6% for NI
Death by injury	QLD, WA, SA & NT	For males: 3x rate in NI For females: 6x rate in NI
Maternal death	Australia	3x rate in NI
Diabetes	Australia	11% prevalence vs 3% in NI
Suicide aged <24yrs	WA, SA & NT	For males: 3% rate in NI For females: 6% rate in NI
End-stage renal disease	Australia	9x rate in NI
Invasive pneumococcal disease	NSW, NT, SA & WA	4.5x rate in NI
Gonorrhoea	WA, SA & NT	48x rate in NI
Chlamydia	WA, SA, NT	8x rate in NI

Table 1: Some aspects of health inequity experienced by Indigenous Australians based on data presented in (Thomson *et al.*, 2004). (NI = non-indigenous).

Interestingly, no statistical work has been located that attempts to tease out financial from non-financial elements of causation of health inequity experienced by Indigenous Australians. There is no doubt that Aboriginal people are, on average, very significantly financially disadvantaged compared to the remainder of the Australian population, and it is equally certain that poverty is a major contributor in the production of their ill-health.

No quantitative analyses analogous to the Nazroo study in Britain or Otten's work in the US appear to have been undertaken in Australia so far, however, to identify clearly the extent to which non-economic aspects of Indigenous disadvantage (such as discrimination, victimisation and postcolonial issues) contribute to health inequity. This could suggest that the two separate but related phenomena of health inequity and financial disadvantage, experienced by Aboriginal and Torres Strait Islander Australians, might have been conflated in the minds of some Australian researchers and policy makers.

Multilevel models of health production remind us that although addressing economic issues will be vital in the mitigation of the health disadvantage of a group, it is also critical to investigate and tackle the full complexity of its causation. There is a risk that the Australian approach to the quantitative study of Indigenous health inequity might fail to appreciate this complexity and analyses such as those undertaken in other settings by Otten and by Nazroo may need to be considered.

#### Gender

Gender as a determinant of health has only fairly recently been considered within an explicit health inequity framework.

It has long been recognised that there are sex-based differentials in human health. A girl born in Australia between 2001 and 2003 has an average life expectancy of 82.8, while a boy could expect to live 77.8 years. (Australian Bureau of Statistics, 2004b)

There are some very clear biological health differentials between the sexes, the extreme examples of which are diseases of organs that are only present in one sex, such as ovarian cancer or epididymitis. Many other conditions such as hypertension and obstructive pulmonary disease also occur at different frequencies in men and women. What has come to be questioned recently, however, is that the presumption that all health differences between females and males are wholly based in biology.

As has been seen in this Chapter so far, the social experience of humans impacts profoundly on their biology and on their health.

The Feminist discourses of the Twentieth Century drew clear attention to the marked differences in social position and experience on the basis of gender in most societies. It would seem inevitable that such differences would have health impacts.

If Whitehead's definition (see page 39) is applied, it can be seen that differences in health status between males and females that result from 'unnecessary, avoidable, unfair and unjust' factors would qualify as examples of health inequity. Sexism would seem to qualify as such a factor, both in its blatant manifestations and also in the complex and subtle ways it constructs accepted roles for males and females in human societies.

Thus in an ecosocial approach to the health outcome of lung cancer would note that currently men experience higher rates than women but would also recognise that this sex differential is reducing over time. This would lead to a consideration of changes in associated factors, and might pay attention to the rising rate of smoking among young women, but would then look beyond that to consider the factors that might have led to this behavioural change. The promotion of tobacco products to women as a previously 'underexploited market' by commercial interests would be likely to come under scrutiny, as well as subtler gendered cultural changes in the way that smoking is regarded.

Equally, an ecosocial analysis of higher rates of road death among young males would certainly consider both the biological determinants of behaviour such as testosterone-based aggressive impulses and also higher rates of alcohol and other drug use among male drivers. It would be interested further, though, in the social constructions of masculinity that determine behavioural mores for males, role stresses that might generate psychological distress affecting driving concentration and increasing perceived need for drug use, as well as the ways that these factors are constructed, amplified and manipulated by powerful interests for commercial and political purposes.

A consideration of the topic of gendered health inequality would be incomplete without contemplating the extraordinary inequity experienced by people of what E.E. Pirelli Benestad has called the 'minority genders'.(Pirelli Benestad, 2001, p 61)

People for whom neither 'male' nor 'female' provides a sense of 'gender belonging' (also a Pirelli Benestad term) and people who feel a sense of belonging in a gender that is different from the one they have been assigned by society are subject to extraordinary social disadvantage in our binary world. This includes people with a variety of identities including transgender, intersex, transsexual, bigendered and ungendered, among many others.

There has been very little systematic research on the health status of minority gender people and none appears to have used a health inequity framework. In 2001 Clements-Nolle and colleagues published a study of 523 people of whom they classified 392 as 'male to female' 123 as 'female to male' and eight as 'intersex'.(Clements-Nolle *et al.*, 2001) The intersex people were excluded from further analysis. They found that 35% of 'female to male' and 2% of 'male to female' people in the sample were HIV positive, about 20% in each group had ever been hospitalised for a mental health problem, and 32% in each group had ever made a suicide attempt. Using the Centre for Epidemiologic Studies Depression Scale they found rates of significant current depression of 62% among 'male to female' and 55% among 'female to male' respondents. No comparisons with 'majority gender' subjects were offered in this paper but the very high rates of health problems seen in the sample suggest marked health inequity.

## Sexual identity as a basis for health inequity

In Chapter 3 the literature on health inequity experienced by homosexually active men will be considered in more detail. At this stage it is worth noting that very little indeed of the medical literature has explicitly adopted a health inequity or health inequality framework to consider the position of people who differ from the majority of members of a society by reason of their sexual orientation identity, same sex attraction or non-heterosexual behaviour.

As a simple example, a Medline search using the criteria '(gay OR lesbian OR homosexual OR bisexual) AND (inequal\* OR inequit\*)' undertaken on February 1<sup>st</sup> 2005 yielded just 19 papers of which only *one* was actually about the health of people of sexual diversity viewed through the health inequalities lens.

This paper, titled 'Lesbian health inequalities: a cultural minority issue for health professionals' was written by Ruth McNair from Melbourne (who, like the author, is an academic general practitioner) in 2003.(McNair, 2003) McNair uses the language of 'health inequalities' but is clearly concerned with issues of health inequity when she says:

Differences in health status for non-heterosexual women result from negative attitudes and experiences within society and the healthcare system, which in turn influence patterns of health-seeking behaviour.(McNair, 2003, p 643)

No other authors appear to have considered sexual orientation or a similar construct (see page 132 for a discussion of the issues around sexual identity terminology) explicitly in a health inequality or health inequity framework.

This is rather surprising, as elements of this approach have had currency in some jurisdictions in recent times. The United States Department of Health and Human Services ten year plan, *Healthy People 2010: Understanding and Improving Health,* for example, acknowledges 'sexual orientation' as among what it calls the 'ways in which health disparities can occur among various demographic groups in the United States' (US Department of Health and Human Services, 2000) and notes that:

America's gay and lesbian population comprises a diverse community with disparate health concerns. Major health issues for gay men are HIV/AIDS and other sexually transmitted diseases, substance abuse, depression, and suicide. Gay male adolescents are two to three times more likely than their peers to attempt suicide. Some evidence suggests lesbians have higher rates of smoking, overweight, alcohol abuse, and stress than heterosexual women. The issues surrounding personal, family, and social acceptance of sexual orientation can place a significant burden on mental health and personal safety.(US Department of Health and Human Services, 2000, p 16)

The plan goes on to commit the United States to 'a multidisciplinary approach to achieving health equity'.(US Department of Health and Human Services, 2000, p 16) More recently, the American Medical Association (AMA) issued a joint statement with the (US) Gay and Lesbian Medical Association in March 2005 that included 'a commitment to fully include the health concerns of gay, lesbian, bisexual, and transgender Americans in the AMA's ongoing work to eliminate health disparities'.

AMA president John C. Nelson went on to say '[i]t's good science, good policy and a matter of basic fairness to ensure that in prevention and treatment of disease and in health research and education, GLBT people are in the mix as much as any other group that experiences disparities'.(Nelson *et al.*, 2005, NPN)

So some of the rhetoric is there but, perhaps tellingly, the US has chosen 'health disparity' rather than 'health inequity' as its descriptor. The Oxford English Dictionary offers two definitions for the word 'disparity':

- 1. The quality or state of being of unequal rank, condition, circumstances, etc.; inequality or dissimilarity in respect of age, amount, number, or quality; want of parity or equality.
- 2. The quality of being unlike or different; unlikeness, dissimilarity, difference, incongruity.(Simpson, 2005, NPN)

Both of these certainly imply 'difference', but neither seems to have prominent ethical or moral evaluative elements that would convey a sense of 'unfair difference'.

The near-absence of writing that explicitly takes a health inequity perspective on people of sexual diversity does not mean that there is no evidence of such inequity in the literature. Though it is dwarfed by the volume of work concerning health inequalities on the basis of socioeconomic position, and to a lesser extent 'race', 'ethnicity' and Aboriginality, a significant body of work comparing the health of gay-, lesbian-, and bisexually-identified people with that of other people in the societies within which they dwell exists. The elements of this literature that concern homosexually active men will be critically surveyed in the next chapter.

# Conclusion

This chapter has provided a brief critical survey of the discourses that surround the concept of health inequity.

It can be seen that the patterning of health status according to social factors has long been recognised and was delineated in considerable detail in the modern period.

The rhetoric of health inequity encompasses notions of equality, fairness and justice that have as part of their genealogy the Universal Declaration of Human Rights (and before that documents such as the French Constitution<sup>\*</sup>).(French Constitution, 1997)

Most study of the phenomenon of health inequity has focused on the patterning of health in relation to socioeconomic position. Smaller bodies of knowledge exist on the relationships between other social categorisations and health.

Multilevel methodologies, such as the ecosocial model proposed by Nancy Krieger, provide a useful theoretical structure for understanding the mechanisms by which social factors, such as the position of gay-identified men in contemporary Australian society, bear on health.

<sup>&</sup>lt;sup>\*</sup> Though, interestingly, not the US Constitution, which fails to include 'equality' among its 5912 words or the 482 words of the attached Bill of Rights.

# Chapter 2: A Primary Health Care approach

# Introduction

The term Primary Health Care appears to be misunderstood by most Australian medical practitioners.

Consider the following scenario witnessed by the author:

A new strategy is being developed for the management and prevention of a particular health condition in an Australian state for the next four years. The condition is one that is largely managed in an ambulatory setting, though without appropriate treatment a proportion of people with it will require intensive hospital treatment and may be at risk of death. The draft policy begins with the phrase 'Our response to [the condition] will be a Primary Health Care response'. At the next meeting of the committee responsible for the strategy, a senior hospital clinician remarks with obvious anger and distress that 'once again the hospital sector has been completely ignored in the thrust of this strategy when we are the ones who have to save people's lives and deal with all the difficult cases!'

Such is the degree of confusion about the phrase that the best place to start may be, as Wass suggests, to be clear about 'what Primary Health Care is *not*'.(Wass, 2000, p 11)

Primary Health Care (PHC) is not, as our hospital specialist seemed to believe, 'primary care', 'primary medical care' or 'general practice' (see page 84 for a fuller discussion of some of these terms). As Wass points out:

Primary medical care (or primary care) is medical care provided for individuals at their first point of contact with the health system ... it is an important opportunity to identify health problems early and provide timely treatment. It is not, however, by itself, Primary Health Care.(Wass, 2000, p 11)

She goes on to point out that PHC is not, either, 'primary nursing', 'communitybased health care' or 'third world health care', since she believes that such misapprehensions are present in various other parts of the health care universe.

What PHC actually *is*, its history, evolution and application in Australia, are the subject of this chapter and provide the context for the employment of the approach in the present study.

## Origins

When the WHO became active in 1948, its Constitution already contained germs of the ideas that have been developed since under the rubric of PHC. The preamble of that Constitution includes the following statements:

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, political belief, economic or social condition.

The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.

Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.(World Health Organization, 1946, p 2)

But, precisely how the governments of the world were to fulfil their 'responsibility' to assist their citizens to achieve 'the highest attainable standard of health' was not spelt out. So, logically enough, many authorities sought to apply the models that had been used in the North America and Europe to the health care of people around the world.

By the 1970s, it appears that there was increasing concern that, as Wass puts it 'all was not well with the world's health and health care systems'.(Wass, 2000, p 7) She goes on to point out that:

[s]ince World War II, there had been rapid growth in the international health care industry without an increase in the health status of many people ... [and] it became increasingly apparent that ... high-technology acute medical care services had a limited effect on the health of populations.(Wass, 2000, pp 7-8)

In this period leading up to the release of the Black Report (see page 31) there was also discontent within industrialised nations about the lack of improvement in the health status of populations despite increased spending on traditional health care provision.

As Cueto points out, there were also a number of publications around this time that were 'influential in challenging the assumption that health resulted from the transference of technology or more doctors and more services'.(Cueto, 2004 1864) He refers to the work of British historian Thomas McKeown who 'argued that the overall health of the population was less related to medical advances than to standards of living and nutrition' and Austrian priest and commentator Ivan Illich who, more radically, 'contended that medicine was not only irrelevant but even detrimental, because doctors expropriate health from the public'.(Cueto, 2004, p 1865)

The parallels of these ideas with the developing study of health inequalities that led to the later development of the ecosocial model of health production (see page 47) are striking. Both lines of thought recognised that the factors that most influenced health, and could most readily improve it, were *outside* of the traditional 'health sector'.

Cueto also points out that there were other, non-Western, models for health *care* provision in existence at the time that it appeared might have much to contribute. He argues that the Indian rural medicine system and the Chinese 'barefoot doctor' scheme (involving 'a diverse array of health care workers who lived in the community they served, ... stressed ... preventive rather than curative services and combined Western and traditional medicines') had prominence at the time, the latter because of China's recent entry into the United Nations.(Cueto, 2004, p 1865)

Cueto charts a shift in the priorities of the WHO in the 1970s, especially under its new Director-General, Halfdan Mahler, who was appointed in 1973. There was an increasing focus on the provision of 'basic health care'. Cueto points to a 1975 joint WHO-United Nations Childrens' Fund (UNICEF) report that again criticized 'the assumption that the expansion of "Western" medical systems would meet the needs of the common people [in] developing countries'.(Cueto, 2004, p 1856) In 1976, Mahler 'proposed the goal of "Health for All by the Year 2000" and pointed out that 'this target required radical change'.(Cueto, 2004, p 1856)

Socrates Litsios was a senior WHO official in the 1970s. In his history of the lead up to the Alma Ata conference, Litsios describes intensive activity in the WHO headquarters at this time, to develop the ideas that would become known as Primary Health Care.(Litsios, 2002, p 720) He also points out that the concepts were not actually new:

Sometime in 1976, I "discovered" the report of the 1937 Intergovernmental Conference of Far-Eastern Countries on Rural Hygiene, held in Bandoeng, Java, in which I found principles in total agreement with those of PHC.(Litsios, 2002, p 720)

## The Declaration of Alma Ata

The first International Conference on Primary Heath Care took place from September 6<sup>th</sup> to 12<sup>th</sup>, 1978 in Alma Ata, the capital of the then Soviet Republic of Kazakhstan.(Cueto, 2004) It was co-convened by WHO and UNICEF and had originally been proposed by the Chinese delegation to the WHO.(Wass, 2000) Cueto points to subtle manoeuvring between China and the Soviet Union, whose leaders were concerned about 'the growing competition [from] the new pro-Chinese organisations that [had] emerged in several developing countries'.(Cueto, 2004, p 1867) This is probably what led to the USSR offering a substantial sum to support the conference, provided it took place on Soviet soil.

The conference was attended by more than 3000 delegates from 134 governments (including the Palestine Liberation Organization and the South West African People's Organization) and 67 international organisations including the International Labor Organization and the Red Cross. It was opened by Mahler who according to Cueto 'challenged the delegates with 8 compelling questions that called for immediate action' and asked whether they were prepared to 'introduce ... radical changes in the existing health care delivery system' and 'fight the political and technical battles required to overcome any social and economic obstacles and professional resistance'.(Cueto, 2004, p 1867)

It appears that, at least for the duration of the conference itself, they were.

The product of the conference, the famous Declaration of Alma Ata, was indeed a radical and visionary document. It called upon 'all governments, all health and development workers, and the world community' to effect significant systemic change 'to protect and promote the health of all the people of the world'.(Declaration of Alma Ata, 1978, p 1)

The Declaration affirmed many of the principles embodied in the Universal Declaration of Human Rights ratified thirty years earlier, naming health as 'a fundamental human right', but controversially (for 1978) recognised that the attainment of 'Health for All' would require 'the action of many other social and economic sectors in addition to the health sector'.(Declaration of Alma Ata, 1978, p 1) It called for 'a New International Economic Order' leading to '[e]conomic and social development' aimed at 'the reduction of the gap between the health status of the developing and developed countries', making the important connection (that seems recently to have eluded some Western powers) that this would 'contribute ... to world peace'.(Declaration of Alma Ata, 1978, p 1)

The Declaration also, rather remarkably, foresaw the discourse that would follow the release of the Black Report two years later (see page 31), when it declaimed that:

The existing gross inequality in the health status of the people particularly between developed and developing countries *as well as within countries* is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.(Declaration of Alma Ata, 1978, p 1, emphasis added)

It laid the foundations for the principle of community participation in the organisation of health and social services with its assertion that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care'.

The document's main definition of Primary Health Care is contained in Article VI and reads:

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of selfreliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.(Declaration of Alma Ata, 1978, pp 1-2)

The focus of this section on health *care,* after reading which the concerns of our troubled hospital physician (see page 63) could almost be understood, is importantly amplified by the seven parts of Article VII, including references to:

- the 'economic conditions and sociocultural and political characteristics of the country'
- health education
- food supply and nutrition
- safe water supply and basic sanitation
- maternal and child health care including family planning
- appropriate immunisation
- prevention and control of endemic diseases
- involvement of non-health sectors including 'agriculture, animal husbandry, food, industry, education, housing, public works [and] communications' with a demand for 'the coordinated efforts of all those sectors'

- education of communities and individuals to enable them to exhibit 'selfreliance and participation in the planning, organization, operation and control of primary health care, making fullest use of ... available resources'
- `integrated, functional and mutually supportive referral systems' with the aim of `comprehensive health care for all'
- a reliance on health care workers 'including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed' all of whom have been 'suitably trained socially and technically to work as a health team and respond to the expressed needs of the community'.(Declaration of Alma Ata, 1978, p 2)

The Declaration concluded with a bold political operationalising of Mahler's call for 'Health for All by 2000' in Article X:

An acceptable level of health for all the people of the world by the year 2000 can be attained through a fuller and better use of the world's resources, a considerable part of which is now spent on armaments and military conflicts. A genuine policy of independence, peace, and disarmament could and should release additional resources that could well be devoted to peaceful aims and in particular to the acceleration of social and economic development which primary health care, as an essential part, should be allotted its proper share.(Declaration of Alma Ata, 1978, p 3)

Viewed from our standpoint twenty-seven years later, the release of Declaration of Alma Ata, and its endorsement by the (Thirty-Second) World Health Assembly in 1979, stand as an extraordinary historical moment of apparent world unity with a focus on the welfare of humankind.

Sadly, of course, this promise was to remain largely unfulfilled.

# Selective Primary Health Care

As early as a year after the Alma Ata Conference, the ideals it espoused were being challenged as 'too broad and idealistic' by health care writers with a more traditional orientation.(Cueto, 2004 1868) This was not surprising since, as Wass observes:

The impact of Primary Health Care represents a real threat to the Western model of health care systems because such systems would have to redistribute their resources and reorient their approach ... even more so with the increased emphasis on privatisation of health care because the provision of high-technology acute care services – not preventing illness and caring for people with timely and low technology services – offers the greatest potential for profit.(Wass, 2000, pp 11-12)

In 1980, Walsh and Warren suggested what they called 'an interim strategy' termed 'selective primary health care',(Walsh *et al.*, 1980, p 145) and in the process also introduced a name for the original Alma Ata approach, which they called 'comprehensive primary health care'.(Walsh *et al.*, 1980, p 146)

They argued that the goals of the Alma Ata Declaration, while laudable, were 'unattainable in terms of [their] prohibitive cost and the numbers of trained personnel required' and argued for 'selective primary health care directed at preventing or treating those few diseases responsible for the greatest mortality in less developed areas and for which interventions of proven high efficacy exist'.(Walsh *et al.*, 1980, p 145)

As Gish pointed out in a 1982 critique however, Walsh and Warren's approach exhibited a 'lack of analytical rigor'.(Gish, 1982, p 1050) The authors quoted a World Bank estimate that suggested that the provision of basic health services would cost 'many billions' of dollars, implying that this would be impossible to raise. What they failed to point out though, according to Gish, was that the developing countries of the world were already at the time spending in excess of \$15 billion dollars per year (and perhaps as much as \$30 billion) on Westernstyle medical care that was not improving the standard of health of their citizens. The Alma Ata Declaration was not only calling for new money (redirected from spending on 'armaments and military conflicts') but also sought a redirection of existing health spending.

Gish also criticised 'selective primary health care' for its focus on curative (or even preventative) technologies with little regard for the means of delivering them. He pointed out that '[t]he existence of, say, a vaccine by itself means little if the health care network is not in contact with the mass of the population', (Gish, 1982, p 1051) an argument that still resonates today in the debate about HIV treatment in the Third World. In this context it has been said that it is no good having antiretroviral medications available if you have no clean water with which to take the pills.

Berman, while recognising the importance of cost-effectiveness analyses in the rolling out of elements of PHC, also criticised Walsh and Warren's model by saying that:

PHC cannot be advanced by technical solutions which ignore factors essential for effective services. Rather, we must seek to improve the effectiveness, equity, and efficiency of primary care in a way that balances the efficacy of medical technology with individual needs and social context, at a cost all countries can afford.(Berman, 1982, p 1058)

None the less, elements of the selective PHC approach were implemented by several agencies in a variety of settings over the following few years. Cueto documents the progress of four such interventions (Growth monitoring, Oral rehydration techniques, Breast feeding and Immunisation) that became known by the acronym 'GOBI'.(Cueto, 2004) He points out that growth monitoring of children proved impractical, and the use of oral rehydration fluids for diarrhoeal illnesses, while lifesaving, was seen by some as essentially a bandaid measure for problems that would only actually be solved by programmes to provide clean drinking water. This situation is strongly analogous to the 'playground at the top of the cliff' story mentioned in Chapter 1 (see page 44) with clean water an apt example of an 'upstream' intervention.

Some elements of 'GOBI' were clearly quite successful but the schism between enthusiasts for selective and those for 'comprehensive' PHC continued.

Newell, himself a former WHO official, writing in 1988, underlined the way in which selective PHC programmes lacked control and participation by the communities they sought to serve. He described selective PHC as 'a threat' and a 'counter revolution' and went so far as to describe the model as 'a form of health service feudalism'. He expressed concern about its attractions to 'funding agencies and governments looking for short term goals'.(Newell, 1988, p 906)

Wass argues that, while selective PHC may reduce the prevalence rates of particular diseases in the short term:

In the longer term it does not deal with the root causes of ill-health, nor does it generate community control over health services or other factors affecting a community's health chances.(Wass, 2000, p 13)

The effects of this difference are pointed out by Rifkin and Walt who give the example of the Kasongo measles immunisation project in Zaire in the late 1970s.(Kasongo Project Team, 1981) They report that although 'a high coverage of measles immunizations resulted in a noticeable reduction in measles mortality' there was no reduction in overall mortality.(Rifkin *et al.*, 1986, p 563) On the same example, Wass observes that '[t]hose children who might have died from measles died from some other cause because the root cause of the problem – poverty – was not addressed'.(Wass, 2000, p 13)

# The Ottawa Charter for health promotion

The first use of the term 'health promotion' is attributed to Sigerist in 1946, but as Breslow points out, the concept grew out of epidemiological studies in the 1950s, 60s and 70s that identified diet, physical activity and substance use as important contributors to chronic disease.(Breslow, 1999) He reports that 'health educators [who were] largely trained in individual psychology, adopted the term *health promotion* to mean their approach to modifying behaviour'. (Breslow, 1999, p 1031, original emphasis)

Wass contends that after Alma Ata 'the Primary Health Care approach [was] taken up as rhetoric by many countries, but with little fundamental change occurring or, where it did, being quickly undermined'.
She argues that this was due in part to 'a belief that it was relevant to developing countries only'.(Wass, 2000, p 11) She suggests that the WHO's development of the idea of health promotion in the 1980s was intended to be 'an approach ... built on the same values as Primary Health Care [but] applied to those issues that would be seen as directly relevant to the industrialised world', in the furtherance of the Health for All by 2000 framework.(Wass, 2000, p 17)

The WHO convened another international conference, this time in concert with the Canadian Public Health Association and Health and Welfare Canada, in Ottawa, Ontario. The preamble to the Ottawa Charter states that what was called the First International Conference on Health Promotion:

was primarily a response to growing expectations for a new public health movement around the world. Discussions focused on the needs of industrialised countries, but took into account similar concerns in all other regions. It built on the progress made through the Declaration on Primary Health Care at Alma-Ata, the World Health Organization's Targets for Health for All document, and the recent debate at the World Health Assembly on intersectoral action for health.(World Health Organization, 1986, p 5)

The conference could easily have adopted the 'individual risk factors and individual responsibility' stand point that had been seen (and in some circles, still is seen) as the logical response to the epidemiological data. Instead it produced a Charter that has been described as 'instrumental in shifting the focus away from an individual, disease prevention approach toward the more fundamental, underlying influences on health'.(Commonwealth Department of Health and Aged Care, 2000b, p 20)

The Ottawa Charter emphasises the importance of public policy in areas outside of health care to the promotion of health through 'diverse but complementary approaches including legislation, fiscal measures, taxation and organizational change'.(World Health Organization, 1986, p 6) It also focuses on the physical and social environments as health determinants and recommends '[s]ystematic assessment of the health impact of a rapidly changing environment – particularly in the areas of technology, work, energy production and urbanization'.(World Health Organization, 1986, p 6)

The Charter goes on to enshrine the principle of community empowerment and 'effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health'. It also calls for the reorientation of health services toward health promotion and emphasises the shared responsibility of 'individuals, community groups, health professionals, health service institutions and governments.'(World Health Organization, 1986, p 7)

Since 1986, the approach encompassed by the Ottawa Charter has been central to countless health promotion strategies and campaigns around the world. It directly influenced the approach of the first South Australian AIDS Strategy in 1987 and the first Australian National HIV/AIDS Strategy in 1989. It has guided our response to HIV that has, despite fraying a little around the edges in recent times, been among the most successful in the world at containing HIV transmission.(Drielsma, 1997) (See page 99 for a detailed discussion of PHC in the Australian response to HIV)

# The Jakata Declaration

The ideals of the Ottawa Charter were reiterated and developed through the WHO's Second (Adelaide, 1988) and Third (Sudsvall, Sweden, 1991) International Conferences on Health Promotion. The Fourth International Conference was held in Jakata, Indonesia, in 1997 and provided an opportunity to reflect on the effectiveness of the Ottawa approach in the ten years since the Charter was drafted.

The resulting *Jakarta Declaration on Leading Health Promotion into the 21<sup>st</sup> Century*, does not differ in its fundamental direction from Ottawa. It appears, more than anything, to be an attempt to rejuvenate a health promotion response in the face of resistant entrenched health care systems and worldwide governmental reticence to embrace it.

Jakarta emphasises the evidence for the effectiveness of 'comprehensive approaches to health development' over 'single track approaches', for the importance of community participation if programmes are to be accepted and for the central role for education in 'achieving effective participation and empowerment of people and communities'.(World Health Organization, 1997, pp 30-31)

It also introduces the notion of 'partnerships for health' between 'government and non-government organisations, and between the public and private sector'.

The Jakarta Declaration goes on to set priorities for the health promotion agenda into the 21<sup>st</sup> Century. These are:

- the promotion of 'social responsibility for health' among decision makers in the 'policies and practices' of '[b]oth the public and private sectors'
- an increase in 'investments for health development' with an exhortation to 'reflect the needs of ... women, children, older people, indigenous, poor and marginalised populations'
- consolidation of `partnerships for health and social development between different sectors at all levels of governance and society
- increasing the capacity of communities and individuals
- securing `an infrastructure for health promotion' including `new mechanisms for funding it locally, nationally and globally'.(World Health Organization, 1986, pp 30-32)

It can be seen that there is little here that was not already present in Ottawa, except what amounts to a call for governments and enterprises to be more socially responsible and to fund health promotion systems. In its last section, the Declaration specifically calls on national governments 'to take initiative in fostering and sponsoring networks for health promotion both within and between their countries' and on the WHO to 'take the lead in building a global health promotion alliance'.[World Health Organization, 1997 #141\, p 32]

## 'Health for all in the twenty-first century'

In 1998, by which time it was patently clear that the goal of 'Health for All by 2000', by any definition, would not be reached, the WHO prepared a report entitled *Health for all in the twenty-first century*. This document described itself as a 'continuation of the Health for All process' and argued that in the (then) twenty years since Alma Ata, PHC 'as the cornerstone of Health for All has provided impetus and energy to progress towards Health for All'.(World Health Organization, 1998, p v) It sought to identify the reasons that this 'progress' had been 'hampered' and suggested that among these were:

insufficient political commitment ..., slow economic development, difficulty in achieving intersectoral action for health, insufficient funding for health, rapid demographic and epidemiological changes, and natural and manmade disasters. Further, poverty has increased worldwide. Health has suffered most where countries have been unable to secure adequate income levels for all.(World Health Organization, 1998, p v)

The report set ten global health targets for the first twenty years of the new Millennium and re-committed the WHO and its Member States to the principle of Health for All. Its proposals were adopted by the (Fifty-First) World Health Assembly on May  $16^{th}$ , 1998 in a resolution that called on 'all peoples and institutions to share the vision of health for all in the twenty-first century, and to endeavour in common to realise it'.(Fifty-First World Health Assembly, 1998, p 2)

#### Developments since 2000

Just before the turn of the Millennium, in September 2000, the United Nations took the opportunity to review the achievements of all of its organisations and, in what became known as the Millennium Summit, consider 'the Role of the United Nations in the twenty-first century'.(United Nations, 2000a, NPN)

In a search for coherence and clarity of purpose for the organisation, the Millennium Summit and the subsequent Millennium Assembly of the UN (the Fifty-Fifth Assembly) pledged the 191 Member States to the achievement of eight Millennium Development Goals as follows:

- 1. Eradicate extreme poverty and hunger
- 2. Achieve universal primary education
- 3. Promote gender equality and empower women
- 4. Reduce child mortality
- 5. Improve maternal health
- 6. Combat HIV/AIDS, malaria, and other diseases
- 7. Ensure environmental sustainability
- 8. Develop a global partnership for development.(United Nations, 2000b, NPN)

It can be seen that all of these goals are related to some extent to health, and that 4, 5 and 6 are specifically population health goals. These very general goals are supplemented with clear targets, to the achievement of which, by 2015, the General Assembly also committed. These include a two-thirds reduction in child mortality under 5 years, a reduction in maternal mortality by three quarters, and a commitment to 'halt and begin to reverse the spread of HIV/AIDS'. They align very closely to some of the ten health targets identified in *Health for all in the twenty-first century* and it is clear that the WHO contributed significantly to their development.

In December of 2001, the WHO received the report of the Commission for Macroeconomics and Health (CMH), which it had appointed in January 2000 'to assess the place of health in global economic development'. (Sachs, 2001) This report argued for a two-way relationship between health and economic development, noting that:

Although health is widely understood to be both a central goal and an important outcome of development, the importance of investing in health to promote economic development and poverty reduction has been much less appreciated. We have found that extending the coverage of crucial health services, including a relatively small number of specific interventions, to the world's poor could save millions of lives each year, reduce poverty, spur economic development, and promote global security.(Sachs, 2001, p vii)

As a later WHO document notes, the CMH report 'challenges traditional assumptions that the health of the world's poor will improve as a result of broader economic development' and calls for additional investments in health.(World Health Organization, 2003b, p 13)

The CMH also noted that 'without such a concerted effort, the world's commitments to improving the lives of the poor embodied in the Millennium Development Goals (MDGs) cannot be met'.(Sachs, 2001, p vii)

In May 2003, in recognition of the coming 25th anniversary of the Declaration of Alma Ata, the (Fifty-Sixth) World Health Assembly, acknowledged the 'WHO's goal of health for all and the progress made by countries to establish primary health care policies and programmes as a cornerstone of their health care systems' but noted that 'much still needs to be done to reach the goal of health for all'.(Fifty-Sixth World Health Assembly, 2003, p 1)

The Assembly's resolution went on the make four requests of UN Member States:

- 1. to ensure that development of primary health care is adequately resourced in order to contribute to the reduction of health inequalities;
- 2. to strengthen human resource capability for primary health care in order to tackle the rising burdens of health conditions;
- 3. to support the active involvement of local communities and voluntary groups in primary health care;
- 4. to support research in order to identify effective methods for monitoring and strengthening primary health care and linking it to overall improvement of the health system.(Fifty-Sixth World Health Assembly, 2003, p 1)

It then called on the Director-General of the WHO to convene a meeting 'with input from all stakeholders in order to examine the lessons of the past 25 years, review definitions and strategies, and identify future strategic directions for primary health care'.(Fifty-Sixth World Health Assembly, 2003, p 2)

This gathering, known as The Global Meeting on Future Strategic Directions for Primary Health Care, took place in Madrid, Spain, from the 27<sup>th</sup> to the 29<sup>th</sup> of October, 2003. In anticipation of the meeting a comprehensive review of the Primary Health Care strategy was undertaken.

This review considered the changes that had taken place in the world since Alma Ata as well as reflecting on the PHC approach itself and proposing some future directions for the WHO in this regard. It took into account the UN Millennium Development Goals and the CMH's report, as well as looking specifically at how PHC had been implemented in various settings through a systematic literature review and regional WHO workshops.

The report of the review draws attention to the following contextual changes since Alma Ata:

- Rapid *changes in the prominent health issues* facing the world such as the appearance and impact of HIV infection, and the 'non-communicable diseases' such as cardiovascular disease, pulmonary disease, injury and mental illness that are seen as reaching 'epidemic proportions in [both] developed and developing countries' and well as the increasing prevalence of chronic illness
- Population demographic changes such as increasing birth rates in some countries, decreasing rates in others, 'a much larger world population of the elderly' and, conversely, dramatic falls in life expectancy in some countries as the result of HIV disease
- Rapid *socioeconomic changes* including 'globalization, industrialization and urbanization' which it sees as 'transforming how populations live, our sense of community, and the determinants of individual health'.(World Health Organization, 2003b, p 3)

It then comments on the uncertainty in some quarters as to the meaning of PHC. It notes that 'it is not for us to suggest a simple definition and to do so would be a mistake' but reiterates and reinforces the 'principles' and 'core activities' of PHC outlined in the Declaration of Alma Ata (and discussed on page 68 of this thesis).(World Health Organization, 2003b, pp 5-6)

Out of this discussion, the review suggests three *strategic imperatives* for PHC into the 21<sup>st</sup> Century:

- 1. Reducing excess mortality of poor marginalized populations: PHC must ensure access to health services for the most disadvantaged populations, and focus on interventions which will directly impact on the major causes of mortality, morbidity and disability for those populations.
- 2. Reducing the leading risk factors to human health: PHC, through its preventative and health promotion roles, must address those known risk factors, which are the major determinants of health outcomes for local populations.
- 3. Developing Sustainable Health Systems: PHC as a component of health systems must develop in ways, which are financially sustainable, supported by political leaders, and supported by the populations served.(World Health Organization, 2003b, pp 6-7)

These 'imperatives' would seem to re-commit PHC, in close to its original Alma Ata form, though with a little 'selective' recasting, and incorporating the elements of the Health Promotion agenda from Ottawa to Jakarta, to the rejuvenated 'Health for All' principle.

The full report of the Madrid meeting does not appear to have been publicly released, but a brief report, which the (Fifty-Seventh) World Health Assembly was 'invited to note', dated April 2004 provides some flavour of its outcomes.(World Health Organization, 2004, p 3) It appears to support the thrust of the review of PHC but some threads of dissent do appear to 'seep through its parchment'. In item 9, attention is drawn to the belief that 'within civil society, individuals have responsibilities and rights for their own health and that of others' and to the truism that 'prevention and care are complementary, not alternative, interventions'.(World Health Organization, 2004, p 2)

While neither of these assertions is seriously problematic in its own right, one can discern overtones of a focus on individual choice rather than social determination in the production of health, and some claim-staking for traditional medical services, that were not present in the PHC review or indeed in the history of PHC in the WHO.

At the time of writing (February 2005), the WHO websites did not appear to give great prominence to PHC. The phrase did not appear on the organisation's (English language) front page (http://www.who.int/en/) or any of the pages directly linked to it.

The only way, in fact, by which it was possible to access information about PHC through the WHO's primary website was through the search function. From here can be found a couple of links to the original Alma Ata Declaration and a link to the European office that leads to a discussion of 'primary care', 'integrated care' and 'hospital to home' programmes.

The only clear reference to PHC on the primary international website was buried deeply in the 'chronic diseases' section and reported the now quite old news that the October 2003 Madrid conference took place.(World Health Organization, 2003a) There was, however, one link to an article from the November, 2004 edition of the Pan American Health Organization Newsletter. It maintained that the 45<sup>th</sup> Directing Council of that body had determined that PHC 'remains key' to its objectives.(Pan American Health Organization, 2004, NPN)

So the division of the WHO with responsibility for North and South America does appear to have retained some focus on the principles of PHC but the remainder of the organisation is not currently seeking to publicise its commitment to the approach. This impression, combined with the subtle overtones in the April 2004 brief report to the World Health Assembly, and the non-release of the full report on the Madrid meeting, raise the question of whether there are forces within the WHO that are seeking to downplay PHC at this point in history.<sup>\*</sup>

<sup>\*</sup> Post Script (May 2005): Since this section was written, there has been one further relevant development in the WHO. Although there has been no further action on the PHC agenda itself, the organisation's new Director General, Dr Lee Jong-wook, does appear to be more committed to some of its principles. On March 18<sup>th</sup>, 2005, he announced the formation of a three year WHO Commission on the Social Determinants of Health. Among the Commissioners he has appointed is Australian academic and health activist Fran Baum who is of the firm opinion (personal communication) that this development signals an intention to shift in the WHO's direction back toward the principles of Alma Ata. Because the term 'Primary Health Care' has become so contested in recent times, and some have sought to exploit confusion around its meaning to divert resources to primary care activities that lack its broad principles (see page 86), it may be that Dr Lee has found away to counter this trend by a new focus on a discourse of 'the Social Determinants of Health'.

Hall and Taylor, in an article published in January 2003 (before the Madrid Conference), referred to 'the demise of the Alma–Ata Declaration'.(Hall *et al.*, 2003, p 17) They argued that the influence of the World Bank on international health policy, through an approach known as Health Sector Reform, has been the cause. They saw this approach as placing 'an emphasis on using the private sector to deliver healthcare services while reducing or removing government services', and having a focus on '[u]ser-pays, cost recovery, private health insurance and public-private partnerships'. (Hall *et al.*, 2003, p 19)

They criticise the Health Sector Reform model, saying that it:

was and is seen in developing countries as being imposed by economists form North America and Europe. As a policy it has not been debated and unanimously agreed to, as PHC was at Alma Ata. Communities in developing countries do not have a say directly or indirectly in their health services. There is no sense of the new approach promoting equity in accessing even the most basic services ... [r]ather, there is a sense of inequity, marginalisation and frustration.(Hall *et al.*, 2003, p 19)

Noting that the World Bank has seldom used the term PHC in its programmes, Hall and Taylor believed that the World Health Report 2000 'marked the end of WHO's use of PHC as the means for the delivery of healthcare services in resource-poor countries'.(Hall *et al.*, 2003, p 19) On the face of it, the Madrid conference ought to have proven this prediction wrong. The ominous signs since the Conference however, despite the upbeat tone of the 2003 Review of PHC, give cause for concern that Hall and Taylor's predictions may just have been a little delayed and that Madrid was, in fact, PHC's last gasp from a WHO standpoint.<sup>\*</sup>

It is certainly the case that the World Bank has carriage of the Millenium Development Goals to a large degree (for example, the Millenium Development Goals website [http://www.developmentgoals.org/index.html] bears only the 'World Bank Group' logo). The Bank argues strongly for an increase in donor nation aid to further those goals but the principles of PHC are nowhere to be found in its view of the world.

<sup>&</sup>lt;sup>\*</sup> It will be argued later that PHC lives on, however, in the activities of community based organisations and the local policy of some jurisdictions.

The second paragraph of its webpage on the sixth Millenium Goal ('combat HIV/AIDS, malaria and other diseases') gives some idea as to the World Bank's justification for intervention on these issues, and it is a long way from Alma Ata:

The economic burden of epidemics such as tuberculosis, malaria, and HIV/AIDS on families and communities is enormous. Estimates suggest that tuberculosis costs the average patient three or four months of lost earnings, which can represent up to 30 percent of annual household income; Malaria slows economic growth in Africa by about 1.3 percent a year; and when the prevalence of HIV/AIDS reaches 8 percent the cost in growth is estimated at about 1 percent a year.(The World Bank Group, 2004, NPN)

Ultimately, it is clear that, in the world at large, the heady promise of Alma Ata remains unfulfilled and the gains that have been made may be under threat. A lack of political will, entrenched health care systems and vested interests in most countries of the world prevented the early progress that would have been necessary for the bold goal of 'Health for All by 2000' to have been met, and threaten the renewed commitment of 'Health for All in the twenty-first century'.

More recently, the further advance of neo-liberal political regimes in much of the Western world and the former Soviet Bloc, with their emphasis on individual freedoms over group responsibilities, have made the dream of Universal Health – like World Peace – seem further away than ever.

Fortunately, however, despite the lack of focus at the international level, nongovernment organisations in several jurisdictions (and at least one regional government see page 112) have continued to uphold and even further develop the principles of Primary Health Care.

Perhaps the best recent operational re-statement of the principles of Alma Ata is the definition of 'progressive Primary Health Care' offered by the (South African) National Progressive Primary Health Care Network:

A progressive primary health care approach:

- 1. challenges the society to address the socio-economic causes of poor health and makes provision for basic health needs
- 2. encourages community empowerment (ensuring that people are fully able to manage resources that are available to them)

- 3. provides comprehensive quality health care including promotive, preventive, curative, rehabilitative and palliative services
- 4. demands concerned and accountable health worker practice
- 5. prioritises the people who are most disadvantaged ensuring that health care is accessible, equitable and affordable to all
- 6. recognises the importance of integrated service provision from primary to tertiary levels of care within a coherent health system
- 7. promotes inter-disciplinary, multi professional and intersectoral collaborative teamwork for development.(The (South African) National Progressive Primary Health Care Network, 2000)

# Primary Health Care, primary care & general practice

The confusion about the meaning of terms that was identified in the scenario at the start of this chapter (see page 63) is extremely widespread and warrants further discussion. Health care workers, policy makers and communities often use the three phrases that form the title of this section without precision, as if they were interchangeable. This is an unfortunate state of affairs and appears very frequently to give rise to misunderstanding and miscommunication.

To make matters worse, a variety of definitions has been proposed for each, compounding the perplexity of anyone who needs to make sense of their use. This section will attempt to define the lines of cleavage between the three ideas and offer a schema for their effective use.

Primary Health Care was defined in the Declaration of Alma Ata (see page 68) and has a specific but rather involved meaning. This meaning includes a requirement that it be the:

first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, (Declaration of Alma Ata, 1978, pp 1-2)

but this should *not* be taken to exclude the possibility of a hospital, for instance, providing a service that has the characteristics of PHC.

If a hospital were to develop an outpatient service to meet the expressed needs of a community, that was developed and controlled in partnership with that community, adopted an holistic view of the production of health and paid attention to the non-biological determinants of health in that community, what it was doing would be PHC. It would not even have to be an outpatient

service. If the same hospital were to provide inpatient respite care for people with a chronic illness who were in temporary need of increased support, or an inpatient sobering up centre, that had been developed in partnership with a community and met the other criteria described, that too would be PHC.

The requirement for all (or at least most) of the Alma Ata elements to be present seems to be even more necessary where the term has initial capitals (Primary Health Care is more Alma Ata than primary health care).

Primary care, on the other hand, means *only* that a service provides care at the 'first level'. The famous grand-pianoed 'medical centres' created by Geoffrey Eddleston in the late 1980s were examples of primary care, but they were certainly nothing to do with PHC.

The European Office of the WHO has recently sought a commonly agreed definition of primary care – for reasons that may be related to the decline of *PHC* in WHO policy discussed above. Their website reports that a meeting was held for this purpose in Barcelona in November 2002, where `[t]echnical experts, nongovernmental organizations and health care professionals' gathered to debate the contested term. (World Health Organization Regional Office for Europe, 2002, NPN)

A couple of extra, confusing, candidates were also debated, namely 'primary medical care' and 'family medicine'.

Perhaps surprisingly, it seems that a consensus was obtained that primary care is 'a span or an assembly of first-contact health care services directly accessible to the public'. The delegates also called for a clear distinction to be drawn in future 'between primary health care (as presented in the Declaration of Alma-Ata) and primary care (which refers to local level health care services)'.(World Health Organization Regional Office for Europe, 2002, NPN)

Interestingly, this WHO definition does *not* include any requirement that these 'directly accessible first-contact health care services' be provided by a medical practitioner. Thus, a district nurse would be a primary care provider, as would a pharmacist.

The misuse of the terms 'Primary Health Care' and 'primary care' as if 'their philosophies and practices were the same' may not be a matter of simple oversight, according to Keleher.(Keleher, 2001 57) She argues that:

it is problematic that primary care practitioners are increasingly provided with funds designated as primary health care funding because it narrows the primary health care agenda. It is symptomatic of a conservative environment that reflects serious policy moves away from comprehensive notions of primary health care. Thus, the use of the language of primary health care in the primary care system demonstrates a conservative policy intent.(Keleher, 2001, p 57)

She goes on to suggest that for primary care as it is currently constituted in Australia to provide Primary Health Care, very significant reorientation and reskilling would be necessary, but she argues that, if we are serious about tacking health inequalities,:

[w]e must endeavour to find and fund, broad based approaches to health creation using the combined strengths of primary care, primary health care and health promotion.(Keleher, 2001, p 61)<sup>\*</sup>

'General practice' might at first seem to be a less contested term, since it is usually taken to imply primary care provided by a medical practitioner. The distinction between 'Recognised' or 'Vocationally-registered' General Practitioners and 'Other Medical Practitioners' on the basis of training or experience, in Australia, identifies another set of tensions however, related to General Practice as a medical specialty.<sup>†</sup> Thus 'Other Medical Practitioners' might provide primary care but perhaps not General Practice.

'General Practice' (with the capitals) has also been formally defined by a number of bodies, such as the Royal Australian College of General Practitioners, which sees it as:

<sup>&</sup>lt;sup>\*</sup> Harris and Furler, in contrast, argue for *primary care*'s ability to 'increase equity in health' but then identify the same sorts of barriers to it doing so as Keleher, such as evidence that GPs spend *less* time with socioeconomically disadvantaged patients and their individualistic disease-management orientation.(Harris *et al.*, 2002, p 35)

<sup>&</sup>lt;sup>†</sup> Or 'medical discipline', as it is sometimes called by the Commonwealth, perhaps because the word 'specialty' like the word 'sorry' might have financial consequences.

part of the Australian health care system [that] operates predominantly through private medical practices, which provide universal unreferred access to whole person medical care for individuals, families and communities. General practice care means comprehensive, coordinated and continuing medical care drawing on biomedical, psychological, social and environmental understandings of health.(Royal Australian College of General Practitioners, 2001a, NPN)

This definition was the result of a formal review in 2001 and differs significantly

from the College's earlier definition:

General practice is that component of the health care system which provides initial, continuing, comprehensive and coordinated medical care for all individuals, families and communities, and which integrates biomedical, psychological, social and environmental understandings of health.(Royal Australian College of General Practitioners, 2001a, NPN)

The addition of a reference to 'private medical practices' suggests a change in the political position of the College and a desire to differentiate General Practice from public services providing primary care or PHC. None the less, the persistence of 'biomedical, psychological, social and environmental understandings of health' implies at least some elements of PHC that do not inhere in the term primary care.

So, to summarise, PHC is what Alma Ata says it was, or something close to it; primary care is just first level health care of any kind, and general practice is first level medical care and may only include care provided by a 'specialised' general practitioner.

# PHC in Australia

#### PHC and national health policy

Australia was a signatory to the Declaration of Alma Ata, and formally committed itself to the 'Health for All by 2000' goal under the Fraser Government in 1981.(Wass, 2000)

Seven years before this, however, Gordon Briscoe, Shirley Smith, Dulcie Flower and Fred Hollows established a shop-front clinic in Redfern, Sydney 'in response to community need' where 'a volunteer doctor and an Aboriginal nurse/receptionist' provided 'affordable, accessible and culturally appropriate health care' to the Indigenous people who lived in the area.(Thiele, 2003, NPN)

The Redfern Aboriginal Medical Service was the first in what soon became a network of Community Controlled Health Services across Australia.

Then, in its 1973 budget, the Whitlam government provided funding for what it called a Community Health Program. According to Browning, the Community Health Centres set up under this programme, 'were to be controlled by the local community, and provide integrated primary health care, including medical and nursing services' as well as 'preventive and advocacy services'.(Browning, 2000, NPN)

It is clear that many of the elements of PHC, as defined later under Alma Ata were already present in some of these fledgling services. Auer charts the early history of Adelaide's Hindmarsh Women's Health Centre, which was born under this scheme, and confirms that under the Medibank package in 1973 there was an aim:

to provide coordinated health and related welfare services based in the community particularly for those with unmet needs. Prevention was to be emphasised and a multi-disciplinary approach was used. The community was to be involved in decision-making processes affecting health care.(Auer, 2003, NPN)

Ironically, it was just after the Declaration of Alma Ata, with a Liberal Federal government under Fraser and the fall of the SA Labor government in 1979, that the Hindmarsh Women's Health Centre had its funding withdrawn and this particular bold experiment came to an end. Raftery argues that this resulted from 'tensions' related to 'the socialist and feminist analysis that the centres used and promoted'.(Raftery, 1995a, p 53)

Fortunately, the movements that had started with Redfern and the Community Health Program proved to have a life of their own and communities have since found ways to maintain or renew services through creative lobbying and cobbling together of funds from a variety of sources. The Community Controlled Aboriginal Health Services movement, in particular, has been tenacious in its adherence to what came to be articulated as PHC principles, and has found ways to provide care, under a ceaselessly changing funding landscape, for thirty years.

Following Australia's formal commitment to Alma Ata and Health for All at the beginning of the eighties, the Hawke Government, which came to power in 1983, established the Better Health Commission, chaired by Derek Llewellyn-Jones, in March 1985. In his speech to launch the Commission, the Minister for Health, Neal Blewett, said that it represented:

the first concerted national effort to change the basic direction of health policy in this country. For far too long, the emphasis on health care in Australia has been on illness treatment rather than prevention. ... Through this Commission, and by gaining a clearer understanding and more successful integration of the social, educational, and environmental influences on our basic health today, we will achieve a higher level of overall health.(Better Health Commission, 1986, p 3)

The Commission's terms of reference included an explicit mention of the need to 'have regard to ... Australia's part in the World Health Organisation's "Health for All by the Year 2000" initiative'.(Better Health Commission, 1986, p 5)

The Better Health Commission was not set up as an expert committee. Along with six people with health expertise, its membership included three Olympic sportspeople (Lisa Curry, Dawn Fraser and Richard Charlesworth) as well as a former ACTU officer (Robert Gradwell), a radio executive (Rod Muir) a 'television personality' (Suzanne Kellaway) and the then Director of the Australian Film and Television School (Anne Deveson). It received submissions from a wide range of organisations and reported in 1986. Its findings, framed in 'health promotion' language, were followed up in 1988 by a plan titled *Health for all Australians*.

This second document was compiled by what was called the 'Health Targets and Implementation (Health for all) Committee', made up of officers from all of the state and territory health departments and the Commonwealth Department of Community Services and Health, as well as a co-opted representative from the Consumers' Health Forum and the Director of the newly commissioned Australian Institute of Health (later the Australian Institute of Health and Welfare). It was chaired by Prof Stephen Leeder from the University of Sydney.

Health for all Australians (HFAA) opened with the sentence:

It should be the concern of all Australians that a nation which can claim to be one of the healthiest in the world harbours major inequalities in health status within its population, (Health Targets and Implementation (Health for all) Committee, 1988, p 1)

and had a distinct focus on health 'inequalities', which had hardly been mentioned in the Better Health Commission's report. While explicitly based on the Health for All concept, the report does not mention Alma Ata. It quotes heavily from documents of the WHO's European Office (where only four years later Margaret Whitehead was to introduce the concept of 'health inequity', see page 39). Interestingly, when it does mention 'primary health care' it does so in a way that is distinctly different from the WHO definition. *HFAA* appears to be one of the first examples of the use of 'primary health care' to mean simply a 'level of care' (that was seen as being already present in Australia), without the implicit inclusion of the elements of principle in the Alma Ata Declaration:

Primary health care is provided at the first level of contact between the consumer and the health care system. ... The primary health care sector includes many disparate components located in the community ... [including] private general practice, retail pharmacies, work and school based medical, dental, nursing and counselling services, government health promotion units, non-government agencies such as Family Planning Associations and community health centres.(Health Targets and Implementation (Health for all) Committee, 1988, p 113)

Indeed, it makes a point of suggesting that elements of health promotion could be *added* to these 'disparate components':

*Changes* within this system [would] offer excellent prospects for integrated, planned and systematic improvements in disease prevention and health promotion. ... The sector can readily integrate consumer and community viewpoints and needs into health planning, delivery and evaluation.(Health Targets and Implementation (Health for all) Committee, 1988, p 113, emphasis added)

This idea that a 'primary health care' exists or existed in Australia independent of the Alma Ata process, but that it could be the substrate onto which the principles of Primary Health Care might be projected is curious and may have been part of the origin of the confusion between PHC and 'primary care' that persists in Australia to this day (see p84).

What was remarkable about *HFAA* though was, according to Wass, that it was 'the first time that a national health strategy document setting goals and targets for the health of Australians had been drawn up'. Further:

[i]n defining the quest for better health for Australians, the report acknowledged the existence of barriers to that quest, both those outside the health system, such as economic and social factors, and those within the system, which it acknowledged is geared to illness rather than health'. (Wass, 2000, p 26)

*HFAA* is not a perfect document, however. Its shortcomings can be understood when it is realised that the committee that drafted it was composed largely of health bureaucrats. Although the report includes rhetoric about `[e]nhancing consumer and community participation in decision making about health care', and probably despite Stephen Leeder's best efforts, it has a distinctly `topdown' rather than `bottom-up' tone in its proposals.

It appears to have set its goals relatively arbitrarily, though they were no doubt informed to some extent by the wider consultation of the Better Health Commission that came before. It had a clear focus on reform of the structures of the health system (particularly arrangements between the Commonwealth and the states and territories) and paid relatively less attention to the impact of non-health sectors on health or the ability of communities to lead their own health promotion efforts.

There is no doubt of the potential benefit of setting goals and targets for the nation's health that allowed the possibility of effective evaluation and consequent improvement.<sup>\*</sup> Inevitably, however, goals have been largely defined in terms of particular diseases. As such, the measures to achieve them constitute 'vertical' programmes that are the antithesis of the principles of PHC. They run the risk of outcomes like those described under 'selective' PHC above, where one specific disease is replaced by another as a cause of morbidity and mortality since the fundamental determinants of ill-health such as poverty, or the malignant effects of an economic system that is driven by pointless consumption, remain (see the example of the Kasongo project on page 72).

<sup>&</sup>lt;sup>\*</sup> Wass, however, points out that constant re-development of these goals meant that in the 17 years between 1981 and 1998 no particular set of goals and targets was reported on more than once and that as a result 'we can make very little comment about progress'. (Wass, 2000, p 30)

These fundamental criticisms can also be levelled at the national policy documents that followed, namely *Goals and Targets for Australia's Health in the Year 2000 and Beyond* in 1993,(Nutbeam, 1993) and *Better Health Outcomes for Australians* in 1994.(Department of Human Services and Health, 1994) These approaches made some attempt to incorporate 'consumer' (though not 'community<sup>r\*</sup>) input and at least mentioned the social determinants of health.

*Better Health Outcomes...*, for example included the following goals:

Reduce the level of health inequalities in Australia

Improve access to all publicly funded health programs and services for members of the community who face barriers of race, culture and language

Strengthen at the Commonwealth and State/Territory levels, intersectoral action to promote healthy public policy and environments; (Department of Human Services and Health, 1994, pp 25-27)

but, in contrast to its disease and 'risk factor' goals whose targets were precise and fully developed, these 'social' goals were listed as having targets that were to be 'developed by December 1995'. It has proven impossible to determine whether these targets were ever, in fact, developed, but the election of the conservative Howard Government in March 1996 meant that they were certainly never implemented.

The most recent phase of public health planning in Australia is characterised by a focus on National Health Priority Areas and began under the Coalition in 1996. The website of the National Health Priority Action Council tells the story of the transition to this approach by saying that the Better Health Outcomes Overseeing Committee (BHOOC), another group of largely Commonwealth, state and territory bureaucrats which was formed in 1995,:

conducted a review of the national health goals and targets process [which] found that the goals and targets were too complex, with too many indicators, no national reporting requirements and *a lack of emphasis on treatment and the ongoing management of disease*. This review led to the development of the national health priority area (NHPA) initiative.(National Health Priority Action Council, 2003, NPN, emphasis added)

<sup>\*</sup> See page 96 for consideration of the distinction between 'consumers' and 'communities'.

It is perhaps no surprise that at the meeting of Australian Health Ministers in July 1996, the first after the election of the Howard government, Australia's national public health policy completed its shift back to a medically-oriented, disease-focused, 'vertically' aligned system with the naming of heart disease, cancer, injury, mental health (which was code for a focus on 'depression', viewed as a 'disease') and diabetes as our National Priority Areas.

This general approach has continued since with the addition of asthma as an additional priority area in 1999 and 'arthritis and musculoskeletal conditions' in 2002.

Since 2000, the programme has been overseen by the National Health Priority Action Council, mentioned above, which is chaired by the Commonwealth Chief Medical Officer and consists of a health bureaucrat from each of the states and territories and two from the Commonwealth (ten in all) as well as a 'consumer representative' and an 'Aboriginal and Torres Strait Islander Representative'.

Even with extraordinary diligence from the two non-governmental people on this Council, it could hardly be described as an organisation that has been structured to facilitate the setting of health priorities by the community whose health they concern.

In fairness, the most recent published strategic statement from the Council does include the following strategy among six 'key directions':

Making demonstrable improvements in health care for disadvantaged groups in each of the national health priority areas, with the aim to reduce inequalities

*Rationale*: disadvantaged groups are the most affected and experience poorer access appropriate care and services. Aboriginal and Torres Strait Islander peoples' health is of particular concern.

*Expected outcomes*: for disadvantaged groups, gaps in care and health services identified for specific focus and attention; new approaches to care identified.(National Health Priority Action Council, 2003, NPN)

This 'direction', while laudable, is of interest since it seeks only to address health *care* inequity (see page 41) rather than health inequity *per se*, and also since its 'expected outcomes' relate to the identification rather than the elimination of such inequity.

References to equity, or more usually to 'inequalities', do continue to turn up in national health policy documents but the usual pattern in recent times is for them to be mentioned in passing and with a sense that their appearance is tokenistic.

It can be seen that despite what Wass calls 'some promising beginnings' in Australia,(Wass, 2000, p 38) little has been achieved overall in the realisation of the ideals of PHC through coordinated national health policy in our country. But, as she goes on:

Within the context of [these] national policies, ... and sometimes despite them, many community health workers around Australia have been working to implement the principles of Primary Health Care and health promotion in their practice. The result has been some inspiring examples of what can be achieved by working in this way.(Wass, 2000, pp 38-39)

And there is no doubt that she is right. Legge and colleagues, in a 1996 report, surveyed the published stories of no less than 185 examples of Australian projects in the early 1990s that might have been considered Primary Health Care.(Legge *et al.*, 1996a) Of these, 99 appeared to have some of the characteristics of PHC.

Reports on these 99 projects were then assessed by expert reviewers who determined that the majority were examples of good practice. Among the 25 best rated (which were studied in depth through field visits and staff interviews), there was a preponderance of projects in women's health, but Redfern Aboriginal Health Service (see page 87) and a number of remote aboriginal health projects were also included, as were a nutritional project at the Parks Community Health Centre in South Australia, health service redevelopments in a couple of rural communities and several school based health promotion programmes.

Further, a number of agencies funded by state governments have adopted and maintained PHC principles over an extended period, in spite of the faltering of support for the approach in national policy. The so-called Family Planning Movement is an excellent example. In South Australia, this movement led to the organisation that is now known as Sexual Health information networking and education (or 'SHineSA'). This entity has an explicit commitment to the

principles of Ottawa and Jakarta in its most recent strategic plan and has organised its outreach services into 'Primary Health Care Teams'.(SHineSA, 2000, p 32)

It is probably no coincidence that SHineSA's *Strategic Directions* also includes a commitment to 'supporting and working towards celebrating the diversity of sexual expression within the community' as well as 'challenging and opposing individual and community views and behaviours which negatively affect the sexual health of others and/or contravene human rights'.(SHineSA, 2000, p 9)

The other development that goes against the tide away from PHC is the Commonwealth's Primary Health Care Research, Evaluation and Development Strategy (PHC-RED), which was implemented by the Commonwealth in 2001, in a process apparently outside of the National Health Priorities Areas approach. The PHC-RED Strategy committed \$50 million over five years 'to foster research capacity-building in Australian primary health care, with a specific focus on general practice'.(Department of Health and Ageing, 2004, NPN) It is a strategy focused only on research, rather than care provision or health promotion themselves, but none the less does appear to be somewhat of a paradox in the general trajectory of Australian policy.

It may be that the explanation lies in the phrase 'primary health care, with a specific focus on general practice', which describes the focus of PHC-RED. There have long been federal policy threads related to *general practice* and to *primary care* that may well have evolved from a recognition of the historical electoral sensitivity of perceived support for 'Medicare', which is seen by many Australian voters to mean the availability of reliable and affordable primary care services.

The PHC-RED programme appears to have arisen out of commitments made under general practice policy. The appearance of PHC in the Strategy may have resulted from a lack of clarity<sup>\*</sup> about the differences between Primary Health Care and primary care at some levels of government, together with

<sup>\*</sup> As Keleher argues (see page 86) this 'lack of clarity' may not be accidental.

advocacy for a PHC approach from the institutions and researchers engaged under the strategy.

Most recently, the PHC-RED strategy has supported the establishment, at the Australian National University, of an Australian Primary Health Care Research Institute.

According to its website, this entity aims to:

Provide national leadership in improving the quality and effectiveness of primary health care through the conduct of high quality priority-driven research and the support and promotion of best practice...(Australian Primary Health Care Research Institute, 2004, NPN)

It has adopted a definition of PHC with a strong Alma Ata flavour, but an emphasis on the primary level of care:

Socially appropriate, universally accessible, scientifically sound first level care provided by a suitably trained workforce supported by integrated referral systems and in a way that gives priority to those most need, maximises community and individual self-reliance and participation and involves collaboration with other sectors. It includes the following:

- health promotion
- illness prevention
- care of the sick
- advocacy
- community development.(Australian Primary Health Care Research Institute, 2004, NPN)

Thus, it seems to be seeking to build a bridge across the confusion in the minds of many about the meaning of PHC (see page 84).

# 'Communities' to 'consumers'

The term 'consumer' appeared to enter into Australia's health policy with *Better Health Outcomes...* (where the phrase 'consumer and community groups' is used),(Department of Human Services and Health, 1994, p 3) and has since largely replaced the idea of 'community' used in Alma Ata.

The Consumers' Health Forum of Australia, which provides the 'consumer representative' for the National Health Priority Action Council, purports to value 'a broad and encompassing view of health, diversity in people, cultures and contributions [and] a fair and responsive health system that minimises inequalities' but interestingly none of these professed values actually translates

into the Goals of its most recent Strategic Plan.(Consumers' Health Forum of Australia, 2004, p 4)

The Oxford English Dictionary's most 'flattering'<sup>\*</sup> of three definitions of 'consumer' is perhaps telling: 'One who purchases goods or pays for services; a customer, purchaser.'(Simpson, 2005, NPN)

This has overtones of the construction of health and health care as 'commodities', with troubling ethical consequences for many, such as Emanuel,(Emanuel, 1997) or Pellegrino, who argues that even the staunchest economic rationalist 'might reexamine that position at the moment when some dear family member is denied access to life-saving or life-enhancing treatments because of the fortuitous operations of the marketplace'.(Pellegrino, 1999, p 248)

The clearly individualist ideas encompassed by the term 'consumer' seem a long way from the collectivist notions of 'community' in the Declaration of Alma Ata.

## The problem of 'outcomes' in PHC

Australia's effective national policy departure from PHC into the National Health Priority Areas approach was justified to some extent by 'a changing focus of accountability in government, from inputs (for example, total expenditure) to outputs and outcomes'.(Australian Institute of Health and Welfare and Commonwealth Department of Health and Family Services, 1997, p 3)

This concept of 'health outcomes', gained currency in Australia in the early 1990s and was crystallised in Australian Health Ministers' Advisory Council's socalled Sunshine Statement in 1993, which, as Legge's group report, included agreement that 'it was vital that the Australian health system should be more strongly focussed on health outcomes so as to achieve optimal personal and community health with the available resources'.(Legge *et al.*, 2003, p 20) The Council defined a health outcome as 'a change in the health of an individual, a

<sup>\*</sup> Among the others is `[h]e who or that which consumes, wastes, squanders, or destroys'.

group of people or population, which is attributable to an intervention or series of interventions'.(Department of Human Services and Health, 1994, p 1)

As Legge and colleagues point out though:

there are aspects of the discourse of outcomes which do not sit so easily with the discourse of primary health care. The discourse of outcomes tends to discount the existential dimensions of health care and the quality of personal relationships because these are not measurable and cannot be reduced to a single objective indicator. It is easier to record the discharge of an acute myocardial infarction than to consider whether a person has been supported in coming to grips with their uncertainties and fears and the processes of remaking themselves.(Legge *et al.*, 1996a, p 21)

The emphasis on 'outcomes' has been a serious challenge for PHC in a time when there has been an increasing shift from what Emanuel & Emanuel call the 'professional model' of accountability for health care to the 'economic model',(Emanuel *et al.*, 1997, p 147) with market based approaches to health funding.

In a peer-reviewed article based on their survey of PHC projects in Australia, Legge's group propose a solution to the problem of providing a 'clearer focus on the outcomes which are presently being achieved in primary health care', from the, perhaps unlikely, field of management theory.(Legge *et al.*, 1996b, p 13)

They argue that the 'traditional ... expert-based ... standards-based approach', by which they mean they systems of explicit goals and targets typified by Australia's National Health Priority Areas methodology, is of 'limited ... applicability ... in the primary health care field', because it 'presumes a domain of knowledge about what works; known relationships between structure, process and outcomes; and knowledge which is independent of the settings in which practice takes place'.(Legge *et al.*, 1996b, p 13)

They suggest that some elements of the 'best practice movement' in management theory provide a useful alternative, since they focuses on 'creating organisational cultures which are directed to the pursuit of excellence' with 'formal standards subordinated to this larger vision'. In this environment, they contend:

practitioners are looking continuously for instances where other people are doing similar things but using different models of practice. Documenting episodes of practice encourages *critical reflection* and the consideration of alternative strategies.(Legge *et al.*, 1996b, p 14, emphasis added)

The notion of 'critical reflection' comes from the adult education literature. It derives from the educational philosophy of John Dewey (1859-1952),(Dewey, 1964) and more recently from Donald Schon (1931-1997).(Schon, 1983) Freire has argued that critical reflection reconciles theory and practice and suggests that 'thinking critically about practice, of today or yesterday, makes possible the improvement of tomorrow's practice'.(Freire, 1998, p 44)

It can be seen that this culture provides a vehicle for accountability and the assurance of quality in PHC without the need for the imposition of external goals, which is antithetical to the PHC principle that communities should determine their own health priorities and control the means of meeting them.

In their review of PHC projects judged to be of high quality Legge and colleagues noted that although:

[m]any of the projects ... have collected data for accountability and reporting purposes, ... the evaluative strategies which appear to be contributing to the excellent outcomes are as much about creating a culture of critical reflection as they are about measuring performance indicators.(Legge *et al.*, 1996b, p 21)

So elements from the 'best practice movement' such as organisational learning and reflective practice provide a means to ensure that demands for effectiveness and efficiency in PHC can be addressed without undermining the PHC approach itself.

# PHC & HIV in Australia

A few specific areas of Australian health policy have been able to resist the move away from a PHC approach, at least until recently. One of these is of obvious importance in a discussion of the provision of PHC for homosexually active men in Australia, HIV/AIDS

The Better Health Commission's 1986 report, mentioned earlier, notes that HIV/AIDS was specifically excluded from the Commission's terms of reference

on the grounds that the Federal Government recognised its 'crucial impact on Australian society' and was taking 'independent national action' to deal with it.(Better Health Commission, 1986, p 8)

That action was what became known as the National AIDS Campaign, followed, in 1989 by the first of four Australian national HIV/AIDS strategies.

As early as 1983, however, within a month of the first Australian death from AIDS, the 'gay community' in Melbourne had formulated the Victorian AIDS Council. On the same day, the Health Minister in the newly elected Hawke Federal Government, Neal Blewett, is reported to have spoken out in the media about the 'growing AIDS hysteria' while the Reverend Fred Nile in Sydney was calling for gay men to be quarantined.(Horsley *et al.*, 2001, NPN) Scarcely a year later, Blewett established the community-oriented National Advisory Council on AIDS (NACAIDS) chaired by Ita Buttrose, as well as a medically-oriented AIDS Task Force. Many of the tenets of PHC have been central to Australia's response to AIDS since this time, before HIV had even been identified as its cause.

Australia's response has been widely regarded as among the most effective in the world and was described by Peter Piot, Executive Director of UNAIDS, in 2001, as one:

where early and pioneering work ensured gay men were driving the response – not driven underground by it. Similarly, Australia provides one of the world's leading examples of the proven success of harm reduction for injecting drug users, with the early introduction of needle and syringe exchange undoubtedly a key factor in keeping HIV rates low among injecting drug users and their sexual partners. (Piot, 2001, p 3)

It seems clear that the PHC principles that have driven this response have been pivotal to its success.

Immediately it was constituted, NACAIDS consulted widely and worked closely with the AIDS-related community organisations that were then springing up in most states of Australia. Its first priority was to support provision of education to the communities that appeared to be most affected, on the little that was known at the time about transmission and prevention of the disease.(Department of Human Services and Health, 1993)

The National AIDS Campaign began in 1986 and explicitly incorporated the framework of the Ottawa Charter, which had been declared earlier that year.(Department of Human Services and Health, 1993 8) Controversially, the Campaign included the famous Grim Reaper television advertisements<sup>\*</sup>, but it also provided Commonwealth funds 'to help State/Territory governments and community organisations to develop "grass roots" AIDS programs and activities'.(Department of Human Services and Health, 1993, p 4)

In 1988, a policy discussion paper titled *AIDS: A Time to Care, A Time to Act – Towards a Strategy for Australians* was tabled in the State and Federal parliaments and a period of extensive consultation with community groups, individuals, agencies and government departments followed.(Department of Community Services and Health, 1989)

In August 1989 this process led to the release of Australia's first National HIV/AIDS Strategy.(Department of Community Services and Health, 1989) The document's subtitle, A policy information paper, belies its extraordinary depth and comprehensiveness. Although it did not mention either the Declaration of Alma Ata or the Ottawa Charter anywhere in its 116 pages, its adherence to both sets of principles was evident throughout. The Strategy summarised the scientific evidence, on which it was clearly based; it emphasised the involvement and leadership of community organisations in the development of the strategy and in its planned implementation; it stressed the importance both of health education and of structural health promotion measures such as the provision of condoms and clean injecting equipment; it proposed a clear research agenda to ensure the continued ability to inform the developing response with the best evidence; it sought to influence public policy for the promotion of health through sections on discrimination, housing, insurance and income support; and finally it committed the Commonwealth and the states and territories to a concrete programme and proposed how the strategy was to be evaluated at the end of its life.

<sup>&</sup>lt;sup>\*</sup> These featured 'ordinary' Australians, including children, as pins in a bowling alley being 'struck' by balls bowled by the skeletal scythe-wielding figure of the Grim Reaper. It has been argued that they markedly increased the stigma experienced by Australians living with HIV at the time.

This evaluation was undertaken in 1992 and the first strategy was judged to have been reasonably effective. By this time there was a perception, according to Feachem, that 'the epidemic appeared to have stabilised' and 'there were indications of a decrease in the incidence of new infections', although '[a]t the same time there was a continuing increase in the incidence of AIDS among people already infected with HIV'.(Feachem, 1995, p 63)

The second strategy contained only minor adjustments but it did mark the first explicit reference to Ottawa in a national HIV strategy when it identified that the:

specific principles underpinning a strategic approach to the HIV/AIDS epidemic reflect a practical expression of the broad principles for health promotion action contained within the 1986 Ottawa Charter.(Commonwealth of Australia, 1993, p 9)

The approach is typified by the second Strategy's assertion that:

[f]unding of education and prevention programs will continue to recognise that the design and delivery of these programs is most effectively taken at community level and by members of the targeted groups, in consultation and in conjunction with government funding bodies.(Commonwealth of Australia, 1993, p 20)

In the foreword to his review of the Second Strategy, Feachem contends that 'Australia is to be commended for the prompt and creative way in which it has responded to this new and special disease' and 'can be proud of its achievements in controlling the spread of HIV and in developing services to provide care and support for people living with HIV/AIDS'. He suggests that 'two features' of the Australian response had contributed to this success and were critical to its maintenance:

first, non-partisan political support, which has allowed pragmatic and effective programs to operate; second, the partnership, which has harnessed the energies of those groups most affected by HIV, government at several levels, and researchers and health professionals.(Feachem, 1995, p i)

In the body of the report he describes this 'partnership', which represents a palpable product of the ideas brought forward at Alma Ata, as '[t]he cornerstone of Australia's response to HIV/AIDS'.(Feachem, 1995, p 59)

Feachem's review led to the development of Australia's third HIV/AIDS strategy *Partnerships in Practice: National HIV/AIDS Strategy 1996-97 to 1998-9 – A strategy framed in the context of sexual health and related communicable diseases*,(Commonwealth Department of Health and Family Services, 1996) which was released in December 1996 by the new Howard Government Minister for 'Health and Family Services', Michael Wooldridge.

In the interval between Feachem's review and the release of the third strategy, there had been some very promising developments in the medical treatment of HIV disease from the first studies of combination HIV treatment involving protease inhibitors. In his foreword to the document, Minister Wooldridge appears to have been extraordinarily supportive of Australia's approach to HIV under his predecessors. He acknowledged the recent medical developments but resisted the temptation to use them to shift the focus away from prevention. He specifically affirmed the important features highlighted by Feachem and contended, in language of which any PHC enthusiast would be proud, that:

[c]ontemporary approaches to public health, as exemplified by Australia's response to HIV/AIDS, recognise that a range of factors impacts on health status. Housing, income security, and the legislative environment all impact on public health, requiring a whole of government response. HIV/AIDS largely affects those most marginalised in our community, and effective responses to this disease require strong leadership and a commitment to non-discriminatory and supportive social infrastructure.(Commonwealth Department of Health and Family Services, 1996,  $p\ v$ )

In the light of the subsequent trajectory of the Howard Government's approach to public health, and in recent times even to HIV policy, this statement is truly remarkable.

*Partnerships in Practice...* has been criticised for starting a process where hepatitis C and sexual health policy was 'piggy-backed' onto HIV policy, to the detriment of all three responses, but otherwise continued the general thrust of the Australian approach.

It was reviewed in 1999 under the auspices of the Australian National Council on AIDS and Related Diseases chaired by former Liberal senator Chris Puplick, and was found to have 'been effective in working towards its stated goals'.(Australian National Council on AIDS and Related Diseases, 1999) By this time, however, cracks were starting to appear in Feachem's 'cornerstone', the 'partnership' between community, government, healthcare and research.

In its summary, the review notes that:

[d]iffering policy positions and objectives between community organisations and governments on various levels have, on occasion, led to difficulties in the practice of the partnership,(Australian National Council on AIDS and Related Diseases, 1999, p ix)

and that:

[t]he community sector has expressed serious concerns about the nature and direction of reform in the public health sector and its implications for the future funding of the HIV/AIDS response as well as a 'whole of government' response,(Australian National Council on AIDS and Related Diseases, 1999, p ix)

while also observing that there had been 'little or no progress' in the programme of legal reform concerning HIV that had been originally proposed in 1992, and that 'political support had sometimes wavered' with regard to clean needle harm minimisation programmes.

The fourth Australian strategy, *Changes and Challenges: National HIV/AIDS Strategy 1999-2000 to 2003-4*, was released in 2000. Minister Wooldridge again provided a foreword for the document but the wording this time seemed a little more restrained. There was no mention in this foreword of the social determinants of health or 'marginalised communities' and the language of 'partnership' had perhaps started to sound tokenistic:

The Strategy *acknowledges* the importance of this partnership and the need to continue to work with partnership members ... (Commonwealth Department of Health and Aged Care, 2000a, p iii, emphasis added)

Mere 'acknowledgement' seems a little lame after saying that the production of the *third* strategy was 'impressive testimony to the collaborative non-partisan nature of the HIV/AIDS partnership in Australia'.(Commonwealth Department of Health and Family Services, 1996, p iii)

The fourth strategy itself still explicitly mentions 'the principles of the 1986 Ottawa Charter' (though it does so by saying that they '*have* been an essential part of our national HIV/AIDS strategies' (Commonwealth Department of Health and Aged Care, 2000a, p 8, emphasis added)), and the rhetoric of community involvement and the other elements of health promotion remains in the document.

In its section on 'people who inject drugs', though, we see the first (albeit very subtle) appearance in an Australian HIV/AIDS strategy of faintly judgemental language in a reference to 'the broader government commitment to countering the threat posed to society by illicit drugs' (and therefore, one might be led to conclude, by the people who use them).(Commonwealth Department of Health and Aged Care, 2000a, p 18)

During the life of the fourth strategy, many believe that the 'wheels started to fall off' the Australian response to HIV. In 2002, under health minister Kay Patterson, an extensive review was commissioned of the fourth HIV strategy, the parallel hepatitis C strategy and of the three National Centres for HIV research. This took place earlier that would have been usual for a five-year strategy and led to speculation that the Federal Government was seeking a new direction for HIV policy in Australia.

The reviews were led by a team consisting of an Australian public health academic (Professor Andrew Wilson), a Canadian public health academic (Liviana Calzavara) and the chief executive of a British AIDS charity (Nicholas Partridge). This group, and the specific review teams working on elements of the review concluded in their report *A journey well started but not finished* that the fourth strategy was 'serving us well in achieving a coordinated, efficient, partnership approach to the control of HIV and the care and treatment of people living with HIV/AIDS' but did make a range of recommendations for improvement.(Wilson *et al.*, 2003, p 3) Of interest, the expert team recommended:

a re-evaluation by the key community partner organisations – gay, injecting drug user, and sex worker organisations – of their constituencies, roles and priorities, particularly in relation to prevention of HIV and STIs and the care of people living with HIV/AIDS.(Wilson *et al.*, 2003, p 4)

Firstly, this recommendation is of interest because it is an example of an 'expert' committee recommending a change of orientation to community based groups, and further because it suggests that the *organisations* do this 're-evaluation', without any exhortation to involve the communities from which they spring and whom they are charged to represent. Both of these elements would seem to be antithetical to the Alma Ata approach. Further, the reviewers had not made the recommendations on their own volition but had been invited to do so through their terms of reference which included a request for 'an analysis of the roles, responsibilities and activities of ...the Non-Government Organisations and community sectors'.(Wilson *et al.*, 2003, pp 31-32)

This top-down approach, was not, as it happens, able to have much immediate impact on these organisations since, for reasons that remain unexplained, the review was not released for almost a year after it was completed and was accompanied by a detailed separate 'government response' to its recommendations.

This response offered few commitments to implementing the recommendations of the reviews, beyond supporting the development of a fifth strategy and the foreshadowed consideration of most of the recommendations through that mechanism. What it did do was to firmly rule out the proposal in the reviews to investigate new harm reduction initiatives relating to injecting drug use, such as supervised injecting rooms and medically-prescribed heroin. The response declaimed that the Australian Government:

strongly believes that medically supervised injecting facilities and the decriminalisation of illicit drugs are not appropriate responses to reduce the demand for and uptake of illicit drugs in Australia. ... The Government does not support a heroin trial in Australia. Such trials would send the wrong message to the community and undermine education and treatment efforts.(Australian Government Department of Health and Ageing, 2003, p 17)

At about the time that she released the reviews and response, in September 2003, a full nine months before the scheduled end of the fourth strategy, Senator Patterson also announced, without further explanation, that the 'term of the Australian National Council on AIDS, hepatitis C and Related Diseases, chaired by Mr Chris Puplick, had expired'.(Patterson, 2003, p 2)

She declared that former Minister Wooldridge, who had since retired from parliament in 2001, would be chair of a new federal advisory body for HIV, hepatitis C and sexual health.

Six days after Senator Patterson's announcement, she was herself the victim of 'review' when a ministerial re-shuffle saw her replaced as Health Minister by Tony Abbott.(Crabb, 2003)

Since his appointment, Minister Abbott has presided over perhaps the most controversial period in the history of Australia's HIV response. In March 2004 he announced the final make up of the new advisory committees mooted by Senator Patterson the previous September. For the first time, Australia's highest advisory group (which came to be known as the Ministerial Advisory Committee on AIDS, Sexual Health And Hepatitis, or MACASHH) did not contain any representatives from the communities most affected bv the diseases.(Wroe, 2004) It did, however, include a retired airforce officer who had also been an official for Australians for a Constitutional Monarchy (Nicholas Hobson DFC, AFC), and a Salvation Army Officer (Major Brian Watters, who was already the chair of Australian National Council on Drugs), while the HIV Subcommittee and the Hepatitis C Subcommittee each included a Jesuit Roman Catholic priest (Father Michael Kelly SJ on the HIV committee and Father Peter Norden SJ on the hepatitis C committee).

In an interview with *The Age* on March 3<sup>rd</sup>, 2004, Bill Whittaker, then Vice-President of the Australian Federation of AIDS Organisations (AFAO), described the appointments as 'particularly bizarre' and went on to complain that 'the appointments that have been made were at the expense of community groups'.(Wroe, 2004, NPN) Mr Whittaker declined an invitation to sit on the HIV Subcommittee because of the exclusion of a community representative from the main committee. *The Age* reported his assertion that the 'exclusion is absolutely unprecedented [and] goes against 20 years of principle'. He went on to describe AFAO as 'extremely disappointed' at the Minister's decision.(Wroe, 2004, NPN)

In the same story, HIV activist David Menadue AO, who *did* accept Mr Abbott's invitation to join the HIV Subcommittee, described the appointees as 'a strange mix of people', and that this represented a significant concern to community groups. He offered the explanation that 'I just think Tony Abbott is thinking, "I want people who share my values and who give me advice I want to hear". 'A spokeswoman for Mr Abbott' is reported to have said that the membership of the committee was 'pretty representative' and that '[b]eing gay was not part of the selection criteria'.(Wroe, 2004, NPN)

Among the tasks of Minister Abbott's new committees was the preparation of a fifth HIV strategy, and in August 2004 a draft was released for consultation.(Australian Government Department of Health and Ageing, 2004)

This document drew widespread criticism for a variety of reasons. Firstly, it included a second section ('Part B'), which purported to be a first 'National Sexually Transmissible Infections Strategy'. It was, however, extraordinarily under-developed – especially given that two years had elapsed since the reviews of the fourth strategy had been received by the Department of Health and Ageing, and the new committees had been working on the document for seven months. Further, it appeared to show no evidence of community involvement in its development despite the explicit re-affirmation elsewhere in the draft of the Ottawa Charter principles. In its response to the draft, AFAO was scathing:

Part B of the Draft is insufficiently developed to be considered a Strategy suitable for adoption as national policy. The bulk of Part B is descriptive and there is a lack of detail about strategic action required to address the problems identified. It is more in the nature of a scoping paper than a Strategy. ... As the first ever attempt to develop a national STI strategy, it is critical that there is broad 'buy-in' from community and professional stakeholders in the Strategy development phase. AFAO does not believe there has been a sufficiently inclusive process ... (Australian Federation of AIDS Organisations, 2004, p 27)

There was also considerable anxiety among community and professional groups that Part B posed the risk of diversion of funds and effort from HIV prevention to a (probably worthy but certainly expensive) National Chlamydia Screening Campaign mooted in the draft.
Stakeholders had vivid memories of the unfunded inclusion of hepatitis C responses in earlier strategies with consequent diversion of scarce funds away from HIV. The Australian Society of HIV Medicine put it this way in its response to the draft:

There may be considerable overlap between our HIV, and STI and viral hepatitis strategies. But there is fear that appearing to 'just tack STI on' could result in disharmony between the disciplines, areas and issues. This was seen in hepatitis C and it has resulted in on-going problems in the sector. These problems continue to haunt those working in both areas. An unnecessary adversarial environment has developed as the various stakeholders have been forced to compete for resources and access to policy and advisory influence.(Australasian Society for HIV Medicine, 2004,  $p\ 2)$ 

The Consultation Draft was also criticised for the inaccuracy of its statistics, for the imprecision of its language,<sup>\*</sup> and for its vagueness generally. There was particular concern about its 'top-down' incorporation (for the first time in the Australian response) of what many saw as moralistic overtones with regard to sexual transmission, such as a requirement that prevention strategies 'include programs developed to stress the importance of avoiding premature sexual activity and the need to for commitment in sexual relationships'.(Australian Government Department of Health and Ageing, 2004, p 19)

The pejorative language with regard to injecting drug use that had first appeared subtly in *Changes and Challenges...*, and more obviously in the Government Response to the reviews of that strategy, seemed almost to reach fever pitch in the Consultation Draft:

The Australian Government does not support or encourage illicit drug use, and is doing its best in conjunction with law enforcement agencies in the States and Territories to stamp out illicit drug use ...(Australian Government Department of Health and Ageing, 2004, p 18)

<sup>\*</sup> For example in some sections, though not others, it used the term 'homosexual men' without apparent appreciation of the critical difference between sexual identity (as in 'gay-identified men') and sexual behaviour (as in 'men who have sex with men' or 'homosexually active men')

These elements, and the constitution of the committees that produced the Draft contrast very sharply with the inclusive, community-oriented, enthusiastic comments of the newly-elected health minister Wooldridge at the beginning of the Howard Government's tenure in 1996 (see page 103).

It has been rumoured that the more extreme elements of the Consultation Draft's rhetoric resulted from the direct annotation of the current Minister on an earlier draft, and this would not seem surprising.(Wroe, 2005)

In November 2004, a national consultation meeting under the auspices of MACASHH was held in Sydney to discuss the draft and the process for further development of a fifth strategy. The author was invited to represent the Australasian Society for HIV Medicine at this gathering and found it to have an extraordinarily adversarial tone, with very little consensus found and no evidence of a functional 'partnership'. The chair of MACASHH, former-minister Wooldridge, appeared, perhaps not surprisingly, to be utterly dispirited and the atmosphere in the meeting room was almost apocalyptic. To the end of May 2005 there had been no further public development in the strategy process, despite an eleven-month hiatus since the expiry of *Changes and Challenges...*. It is clear, however, that much will need to have altered from the Consultation Draft, and a revision of the membership of the advisory structures will be required, if our HIV response is again to approach the PHC principles that many believe were the vital determinant of its early success.

On World AIDS Day, December 1<sup>st</sup>, 2004, Minister Abbott delivered a speech to launch AIDS Awareness Week.(Abbott, 2004) The text of this oration makes Mr Abbott's preferred approach to HIV clear. Laudably, he argues that 'AIDS is a health issue, it's not a moral issue' but then immediately undermines this apparent principle by declaring (somewhat nonsensically) that '[w]e're certainly entitled to make judgements about behaviour, but we shouldn't be judgemental about people'.(Abbott, 2004, NPN)

This strategy of stating a principle then undermining it continues with:

AIDS awareness week should not be an occasion for moralising. There should be no moralising about personal choices, and, also no moralising about an allegedly discriminatory society, because, in Australia's case, it just wouldn't be true.(Abbott, 2004, NPN)

Surely, if the Minister truly believed in the principle in the first sentence above, he would have refrained from undermining that statement with the 'cheap shot' that followed. Further, to suggest that Australia today is free from discrimination shows either astonishing naïvety or extraordinary insensitivity. The high prevalence of suicidal behaviour documented in same sex-attracted young people (see page 170) makes Mr Abbott's comment almost obscene.

In terms of the focus of this discussion on the principles expounded at Alma Ata, however, the following comments from the Minister's speech are most telling:

I want to assure everyone that the Australian government will continue to provide the best possible *medical* care to people with AIDS. The Australian Government will continue to promote the best possible *information* to at risk groups. ... But I should also say that government can't be everyone's keeper ... In the end, it's personal behaviour, not governmental behaviour which largely determines the rate of HIV/AIDS infections. Government will do whatever it reasonably can to alert people to risks, but, in the end, it's up to them whether they heed the message. I have to say that, in the end, the success of Australia's AIDS policies is not due to government, so much as the determination of people with AIDS *to act responsibly*.(Abbott, 2004, NPN, emphasis added)

On first glance, the language in this passage, like many political speeches, appears to be that of 'common sense'. On closer analysis, especially of the words and phrases italicised, it can be seen to deny completely the possibility of social factors influencing the adoption of health promoting behaviours, and the complexity that inheres in risk-taking. Instead, it does exactly what the Minister said we shouldn't and moralises, adopting an 'individual responsibility' approach, with an overtone of 'blaming the victim'. The reference to 'medical' care also denies multidisciplinarity in care, and renders invisible the impact factors outside of the health sector on the production of health.

So in the final analysis, the principles of PHC appear now to be have been abandoned in our national response to HIV, as they have been in most other areas of Federal health policy.

Perhaps it is a coincidence that the rate of new HIV infections in Australia started to rise again at the end of the 1990s, after a steady decline since 1985. Perhaps it is not.

# New South Australian PHC policy

As has already been alluded to, South Australia has, at several times in its history, been at the forefront in the implementation of PHC-based programmes (see discussion of the Hindmarsh Women's Health Centre on p 88). A 1995 book edited by Frances Baum, charted the development and achievements in SA that contributed to the 'Health for All' goal in the twenty year period from the early 1970s.(Baum, 1995) As Raftery observed in the first chapter of that book, in a 1986 review of the Community Health Program:

South Australia appeared, if not as a shining light, then at least as distinctive. ... it had an overall sense of direction and coherence, and was successfully fostering local autonomy and experimentation.(Raftery, 1995b, p 27)

This 'distinctiveness' has experienced several highs and lows in the period since 1986, but is currently undergoing something of a revival.

Soon after it took office in 2002, the Rann Labor Government commissioned what it called a Generational Health Review, lead by John Menadue AO, 'to develop a framework to guide the South Australian health care system over the next 20 years'.(Rann *et al.*, 2003, NPN)

This major piece of work was (as we have seen, most unusually for Australia in the Twenty-first Century) thoroughly and explicitly<sup>\*</sup> supportive of the principles of PHC:

<sup>&</sup>lt;sup>\*</sup> Though there are moments in the Generational Health Review report when there is some blurring of the distinction between PHC and Primary Care

South Australia's proposed future health care system will have a strong primary health care focus with more integrated, coordinated and responsive services, addressing individual and population needs. It will pursue opportunities for health promotion, illness prevention and early intervention with the inclusion of public health functions as key facets of the proposed system. (Menadue, 2003, p 61)

And:

The public has a right to have a say on public health system issues and directions. The right to have a say means the provision of opportunities for involvement across the health care system at all levels. This includes opportunities for community members to be involved in the design, directions and policies of their local health services as well as the right to be involved in decision-making processes at the whole-of-health-system level.(Menadue, 2003, p 103)

What is more, the South Australian Government, has actually started to implement some of these, now radical, recommendations. On September 12<sup>th</sup>, 2003, exactly twenty five years after the Declaration of Alma Ata, Health Minister Lea Stevens launched a new *Primary Health Care Policy* for South Australia, (Department of Human Services, 2003) and invited stakeholders to commit to the *Adelaide Affirmation for Primary Health Care*. (Government of South Australia, 2003)

It would be easy to be cynical about the importance of the Affirmation, entered into at a state level, and to see it as a grandiose gesture with little meaning. That would be to deny, however, the power that such statements of principle have to inspire, and to fail to understand how remarkable it is that a small jurisdiction in Australia has re-discovered and re-affirmed the tenets of PHC against an almost irresistible national and international tide.

The Adelaide Affirmation refocuses Primary Health Care for our place and times but loses nothing of the meaning of Alma Ata in doing so. Although it aroused little fanfare at the time it was made, it can be hoped that over the next twenty-five years it will come to be recognised as a turning point when the tide of individually-oriented 'illness care' began to turn back toward a focus on health. It is reproduced below in full (with its original bolding) as a fitting conclusion to this chapter.

# Conclusion

This chapter has considered the history of the Primary Health Care approach and examined the extent to which its principles have informed global and Australian health care policy since the Declaration of Alma Ata. The trajectory of HIV policy has been tracked in particular detail because of its contextual relevance for the application of a Primary Health Care model in the present study. The next chapter will consider the third term in the title of the thesis, 'homosexually active men'.

Adelaide Affirmation for Primary Health Care. September 12, 2003.

We stand on Kaurna Land and with the Kaurna people we affirm our commitment to build **Health for All**. To build **Health for All** means to build a better life for all.

Health comes from our land, our families, our communities and cities. Health comes from our states and our nations. Our health is built by working together. Health is our global concern.

Whatever supports and promotes our health must be accessible to all of us,

- Our economies must be health promoting
- Our environments must be healthy and sustainable
- Our cultures must be reconciled
- Our diversity must be respected
- Our conflicts must be resolved in peace and justice, and
- Our health systems must be built from the ground up.

We stand by our commitment to the Alma Ata Declaration for Primary Health Care. **Health for All** is our fundamental right.

Primary Health Care did not start with Alma Ata - but Alma Ata gave us a way forward.

To build health and to build primary health care means,

- We insist on public participation in health decisions
- We promote partnerships between consumers and providers
- We bridge the distance between service providers
- We ensure health services are integrated
- We deliver safe health services based on the evidence of what works
- We take action to promote health across all levels of government and the community, and above all else
- We advance the democratic principles of openness, inclusion and equity.

Alone - we cannot build health

Alone - we cannot build primary health care

But together we can.

Health comes from us all

**Health is for All**.(Government of South Australia, 2003, NPN, original emphasis)

# Chapter 3: Homosexually Active Men

# Introduction

This chapter will summarise the history of the construct of 'homosexuality' and discuss the issues related to homosexual categorisation and identity. It will then attempt to summarise critically what is known about the health of homosexually active and gay-identified men in comparison to the health of other men, with a particular focus on the Australian setting, to provide a context for the findings of the present investigation.

# A brief history of homosexuality\*

# Beginnings(?)

There were no homosexuals before 1869.

Or so Queer theorists would have it.

It was in this year that Karl Maria Kertbeny coined the term 'homosexual' (as *Homosexualität,* in German) to identify a category of people who enjoy sexual activity with members of their own gender, as part of a complicated taxonomy of sexual appetites.(Wikholm, 1998) His work followed the description of male 'Urnings' (based on Plato's association of the love of men by men with Uranus) in 1864, and of female 'Urningins' in later work, by Karl Heinrich Ulrichs.

<sup>&</sup>lt;sup>\*</sup> The first section of this chapter is adapted from part of a published chapter coauthored with psychologist, Mr Adrian Booth.(Rogers *et al.*, 2003a) The author wrote the first draft of the section in question personally, with Mr Booth (and the editors of the volume) contributing suggestions and modifications. It is included with the coauthor's permission.

Although they worked separately, both Kertbeny and Ulrichs believed that humans could be sorted into categories according to their sexual orientations, rather than simply by their actions, and that such categories reflected their inborn natures rather than external influences or deliberate choices.

Both men appear to have been motivated by beneficence for the people they so categorised. Ulrichs saw himself as having 'the soul of a woman' in the body of a man and sought to further the welfare of others of his kind.(Kennedy, 1988) While Kertbeny loudly – perhaps too loudly – protested his own heterosexuality (a term he also coined), his position was a liberal one.(Féray *et al.*, 1990) He claimed to have been influenced by the experience of a teenage friend who suicided under threat of blackmail and seems, like Ulrichs, to have hoped that 'once homosexuality was recognized as an inborn propensity and not a moral failure, the courts would stop jailing homosexuals'.(Wikholm, ND , NPN)

This did not, of course, happen. Paragraph 175 of the German Penal Code, against which both were protesting, was adopted in 1871 and remained in place until 1969, but the most important impact of these two men was that after them there was an academic language to refer to a *type* of human who was homosexual, rather than solely to same-sex-directed *behaviour* among humans in general.

Michel Foucault, writing in 1976, described the consequent paradigm shift as 'a new *specification of individuals'*.(Foucault, 1976/1998, pp 42-43, original emphasis) He observed that, while formerly 'sodomy was a category of forbidden acts [and] their perpetrator was nothing more than the juridical subject of them', at this time the homosexual:

became a personage, a past, a case history, and a childhood, in addition to being a type of life, a life form, and a morphology, with an indiscreet anatomy and possibly a mysterious physiology ... The sodomite had been a temporary aberration; the homosexual was now a species.(Foucault, 1976/1998, p 43)

#### Medicalisation

Ulrichs was a lawyer and Kertbeny a journalist. With their professional voices they were well placed to argue for social change but, at this point in the Nineteenth Century, needed allies from the field of medicine, which was beginning to claim expert authority in many areas of human life, including sex.

A third Karl, Berlin psychiatry professor Karl Frederick Otto Westphal, appears to have been the first to describe a medical *diagnosis* of same sex attraction. In an 1869 paper he described the condition of 'die conträre Sexualempfindung' (literally 'contrary sexual feeling'), which became 'sexual inversion' when slightly mistranslated via Italian into English.(Westphal, 1869, NPN) Even in the original German, the 'conträre' sees homosexuality as what Norton calls a 'contradiction between desire and anatomy'.(Norton, 2002, NPN) In the thinking of the late Nineteenth Century, with its notions of the perfection of nature, this 'contradiction' has a clear connotation of abnormality that contrasts sharply with both Ulrichs' and Kertbeny's purely descriptive postures.

Richard von Krafft-Ebing, another psychiatrist to whom Ulrichs had sent his original work, consolidated this view of homosexuality as both aberrant and undesirable – that is pathological – in his 1886 *Psychopathia Sexualis,* which 'announced itself as a "medico-forensic study" of the "abnormal"' (cited in Weeks (Weeks, 1985, p 68)). Krafft-Ebing was also a campaigner against the criminal prosecution of homosexuals (at least those in whom he saw the 'perversion' to be involuntary), but the view of them as victims of a 'degenerate disease' began a tradition that remains alive in some academic circles to the present. According to Foucault, the nascent specialty of psychiatry 'annexed the whole of the sexual perversions into its own province' at about this time, and the medicalisation of sexuality, and homosexuality, had begun.(Foucault, 1976/1998, p 30)

Havelock-Ellis, Symonds, Hirschfeld and Freud, among many others, explored the phenomenon of homosexuality further but almost all scholarly work remained within the clinical model, that had begun with Westphal, until the 1950s.

#### Study outside of pathology

The symbolic beginnings of the end of this era of pathology (for its remnants linger on) were the surprising descriptive statistics of the 'Kinsey Report' in 1948,(Kinsey *et al.*, 1948) followed by the celebrated work of Evelyn Hooker, first published in 1957.(Hooker, 1957)

Dr Hooker was an academic psychologist at the University of California, Los In the late 1940s she became acquainted, through one of her Angeles. students, with a circle of homosexually-identified men.(Herek, 1997) She seems to have been interested in, and probably surprised by, the apparent mental health of her new friends. In 1953 she was convinced by them to apply for funding to undertake what appears to have been the first study of the mental health of homosexuals who were *not* already in contact with a mental health clinician. With the hypothesis that the 'adjustment' (a term in vogue at the time) of non-clinically recruited homosexuals would not differ from that of similarly recruited heterosexuals, her design was simple and elegant. She administered three standard psychometric tests that were in common use in the 1950s (including Rorschach's famous ink blot) to a group of homosexuallyidentified and a matching group of heterosexually-identified men. The results were scored blind by 'expert' judges who could discern no difference between the groups. Furthermore, they were unable to identify the sexual orientation identity of the respondents from their Rorschach results.

Hooker's work has had its critics (eg Landess, ND) but its importance lay not in its scientific rigour *per se*, nor even its validity, but rather in its theoretical starting point. Her study did not need to demonstrate that rates of mental illhealth were really no different between gays and straights (this outcome would indeed be unlikely if we believe social stress has any causal effect on mental illhealth) but merely that there was no *intrinsic* relationship between homosexual identities and mental illness. When Hooker found that her sixty, albeit well educated and activist, homosexuals were just as mentally healthy as sixty opportunistically recruited heterosexual men, she proved that such a state of affairs was neither impossible nor even uncommon.

At a stroke, she created a new (or, the spirit of Ulrichs would argue, rediscovered an old) paradigm of thought about homosexually-identified people and laid the foundations for the gay liberation movement.

#### Gay liberation and the 'ethnic' model

The 1960s were clearly a time of great ferment for the Western world and, for most readings of history, the 'sexual revolution' was a central theme. For some authors it was indeed the *cause* of the tumult. As Ridgway put it,(Ridgway, 1997, NPN) '[s]exuality became political, emerging as an axis around which new social movements organised'.

Against this background, the thinking space made possible by Kinsey and Hooker was occupied by activists like Frank Kameny, who was one of the first victims of the McCarthyite purges of US federal employees to fight back.(Altman, 1971) A 'homophile' movement grew through organisations like the Mattachine Society and the specifically lesbian Daughters of Bilitis.

As both Nietzsche and Foucault have argued, history is not linear but rather a complex web of ideas, interactions and influences on individuals and groups. The founders of gay liberation were not entirely liberated themselves and, as Altman put it, still had 'a certain apologetic tone, as if homosexuals were agreeing that homosexuality was abnormal, while pleading to be given a chance to show others just how square – if not straight – they could be'.(Altman, 1971, p 126)

By the end of the sixties, though, the style 'of a pressure group' was giving way to greater militancy and in the summer of 1969, on the day that the icon of lovelorn queens, Judy Garland was buried, there occurred what Altman called 'the Boston Tea Party, as it were, of the [gay liberation] movement'.(Altman, 1971, p 126)

At the Stonewall Inn, a bar on Christopher Street in Greenwich Village, New York City, the police undertook one of their regular raids of gay venues, on the pretext of liquor law violations.

On this occasion, however, the outcome was different. The people of sexual diversity who were its patrons fought back, occupied the premises for three days and shouted the tenets of gay liberation on the streets. As Lucien Truscott (cited by Altman, 1971, p 127) observed, 'the sudden specter of "gay power" erected its brazen head and spat out a fairy tale the likes of which the area has never seen'.(Truscott, 1969)

The Stonewall riot has been seen as a symbolic turning point, and there was certainly a rapid flurry of activity in the months that followed. The New York Gay Liberation Front was founded in the days immediately after the riot and by the end of 1969 the newspaper *Come Out!* was in production. Australia's first major gay organisation, Campaign Against Moral Persecution (CAMP), formed in 1970 and by the end of 1971 had a gay liberation agenda.

During this period of militancy at the beginning of the seventies, the goal of many gay liberationists, in common with black and feminist activists, was radical transformation of the social system that oppressed gays (as well as blacks and women). Very rapidly, however, a more conservative, so-called 'ethnic' model, gained ascendancy. As Spargo put it, the model:

presented gays and lesbians as a distinctive minority group, equal but different, and worked to achieve rights and legal protection within the existing order.(Spargo, 1999, p 29)

This approach, which aimed to bring about social change slowly and subtly without 'frightening the horses', indeed resulted in extraordinary outcomes in Australia.

South Australia, under the Dunstan government, struck out its criminal laws relating to consensual sexual contact between adult males in private in 1975 and most of the other states followed suit soon afterwards. Although Tasmania did not achieve this basic law reform until 1997, it made up for its tardiness by introducing comprehensive anti-discrimination legislation the following year.

Proponents of the ethnic model also aimed at 'the promotion of "positive" images of gayness', (Spargo, 1999, p 30) and in Australia had allies in the media. In 1973, the character of Don Finlayson, played by Joe Hasham, appeared in the popular television series *Number 96*. Finlayson was a very ordinary, though sensitive and likeable, lawyer whose gayness was unconcealed but appeared to be almost incidental to his role in the series. There are Australian gay men who say that the inclusion of this character (some twenty years before US and UK television felt able to handle 'out' homosexuals) did more for their welfare in society than any street march.

A recent Australian interview-based study by McKee confirms this impression. His respondents pointed strongly to the importance of such characters in the development of their self-esteem. He observes that, particularly for gayidentifying young people who are isolated from others, '[f]ictional television forms allow viewers to form a sense of the community in which they live, and their place in it'.(McKee, 2000, p 92) He goes on to maintain that his interviewees found that:

the characters ... allowed them to feel there were other gay people in the world. As for the uses made of these particular characters, they made them 'feel good', gave them something to 'identify' with, or a 'role' to play.(McKee, 2000, p 92)

On the basis of his research, McKee argues that media producers have a 'particular responsibility', since with regard to gay men 'they contribute to the formation of identity and therefore self-esteem in a vitally important way'. In conclusion he goes as far as to suggest that:

[t]he exciting possibility of health researchers and media producers working together might allow for an important intervention to be made in the rates of suicide and attempted suicide of young gay men in Australia.(McKee, 2000, pp 95-96)

Despite its success, the 'ethnic' approach to social reform has borne some valid criticisms. Chief amongst these was that the model was driven by well-off, educated, white men and as such was blind to the concerns of homosexually-identified people who were not also members of this relatively advantaged group.

Furthermore, as a strategy, the 'ethnic' approach relied on the presentation of a sanitised, conformist, vanilla model of the 'acceptable homosexual'. Polygamy, sadomasochism, transgendered expression and even bisexual behaviour all implicitly challenged both the unity of *an* 'ethnicity' and the acceptability of such an 'ethnic' group for assimilation into mainstream society. As Spargo put it:

If you want to be an equal part of the straight world by proving how ordinary, how 'just-like-you' (but perhaps a bit more sensitive or artistic) you are, it simply won't do to flaunt your more excessive, transgressive desires or relations.(Spargo, 1999, p 31)

So this model clearly has its limitations and has the risk of itself being oppressive as it attempts to liberate. But the opportunity that identity-based understandings afford for what Pirelli Benestad calls 'belonging' is real and valuable for many lesbian and gay people. (Pirelli Benestad, 2001, p 65)

# **Queer theory**

Allusion has already been made to the work of Michel Foucault. For him, and some other post-modern thinkers-about-sexuality, the lesbian and gay identities into which the activists of the seventies (and millions of men and women since) 'came out' are an illusion. Or at least they are artifacts that are entirely socially constructed.

Under a social constructionist view of the history of sexuality, the moment when Kertbeny said '*Homosexualität*' out loud (Foucault wrongly attributed this honour to Westphal), a new way of thinking about sexuality began and the homosexual 'species' was born. Only from that time on, they say, could humans identify themselves as belonging to a distinct group, a variant within our kind that had common experience, common concerns and might develop a sense of fellowship.

It mattered not to Foucault that there is evidence of same sex subcultures dating back at least several hundred years before that moment, whose members, it is clear, saw themselves as inherently different from others and had terms for themselves such as 'tom' (for women) or 'molly' (for men).

Nor did he regard as relevant the experience of many lesbian and gay people who feel excluded from general society from an early age and imagine themselves unique in the world until they hear about the homosexual 'species'. In this regard, it is especially enlightening to recognise that the phenomenon occurred even *before* the 'species' had been defined. According to Dynes:

A curious outcome of ... centuries of oppression is that when the first writings on homosexuality reached the general public at the end of the nineteenth century, some individuals revealed to psychiatrists that, although they had responded solely to members of their own sex since adolescence, until then they imagined themselves unique in the whole world. They had 'constructed' their own sexual consciousness without any social input – a feat that should be impossible according to social constructionist postulates.(Dynes, 1990, p 34)

That many of the means of *expression* of a gay or lesbian identity are socially constructed is irrefutable. The language of molly, tom, faggot, homosexual, tribade, dyke and queer; the outward personae from nelly queen to leatherman, from diesel dyke to lipstick-lezzo; the literature, meeting places, newspapers and parties are clearly the product of social (and often economic) forces. That the forces of social power profoundly impact on human sexual behaviour is also undoubtable; ask any poof who has wanted to hold the hand of another man in a public place.

What it can be argued exists independent of its social context, though, is a deeply felt sense of identity that is initially experienced as a difference from the majority and then recognised as membership of, and belonging with, a minority. Although this sense is perhaps best explained by a biological origin for sexual orientation, social constructionists would see it as the keen experience of the social construction of difference as a formative aspect of the subjectivities of gay men and lesbians (see also page 133 for a discussion of the study of sexual identity).

#### The benevolent forensic imperative

It is important to distinguish arguments around social constructionism versus essentialism – that is the question of the *validity* of self-identification as having a homosexual identity (however it originates) – from explorations of the *causes* of homosexuality (or for that matter heterosexuality).

Through much of the history that has been sketched, from Ulrichs to the present, there has been a search by many for proof that homosexual behaviour resulted from a person's nature and thus, it was argued, was beyond her or his control.

These efforts appear to have been driven by a desire for justice and what might be called the benevolent forensic imperative. This idea is related to the legal concept of *mens rea,* which requires that for many crimes, perpetrators can only be considered guilty if, in addition to committing the illegal act (the *actus reus*), they had the necessary mental element and chose to do so in knowledge of the likely consequences.

In the context of homosexual activity, the forensic imperative might be boiled down to 'they can't help it so shouldn't be punished for it (even though it is wrong)'.

The imperative motivated many researchers of good will and indeed has probably resulted in much of the law reform achieved but, as the preceding bald statement of it demonstrates, is flawed in that it assumes the 'wrongness' and starts from there in its benevolence.

If one stops believing that homosexual activity is inherently wrong – which is easy from an ethical framework since of itself it harms no-one, prevents the harm of sexual frustration and allows people to follow their autonomous desires – the imperative disappears.

The study of the determinants of sexual orientation and desire remains interesting but is quite separate and removed from questions of liberation, law reform and societal change.

The extent to which people chose their sexual expression becomes irrelevant once society recognises that what *is* wrong is the prohibition of any autonomous expression of humans through activities that cause no harm to others. (See page 141 for an ethical analysis of sexual diversity.)

It is interesting that Foucault was silent on the 'cause' of homosexuality. When asked about the nature versus nurture debate around the origins of the phenomenon he reportedly responded 'On this question I have absolutely nothing to say'.(Halperin, 1995, p 4)

According to Spargo:

Instead of pursing the illusory 'truth' of human sexuality, Foucault set out to examine its production. His concern was less with what 'sexuality' is, than with how it functions in society.(Spargo, 1999, pp 13-14)

#### The new biology

The most recent chapter in the quest driven (as has been shown, mistakenly) by the forensic imperative concerns the work of gay-identified neuroanatomist Simon LeVay,(LeVay, 1996) and geneticists like Dean Hamer.(Hamer *et al.*, 1993) Despite strident (and at times convoluted) criticism by social constructionists (such as Hegarty, 1997) there appears to be some credible evidence of neurobiological and genetic differences between homosexually self-identified and heterosexually-identified men (there is much less evidence for such differences in women).

This work is of scientific interest for its own sake but as has been argued, it ought to be utterly irrelevant to the legal and social position of homosexuallyidentified people, and therefore, probably, to issues of health inequity.

What LeVay does alert us to, however, is the potential for the (mis)use of this biological knowledge to bring about new 'treatments' for homosexual orientation (conceived of as disease) and even prevention of the birth of homosexual people through antenatal diagnosis and abortion. These issues could well contribute to the future oppression of people of sexual diversity, and require a careful watching brief from those who work against health inequity.

#### **Recent history**

Around the turn of the millennium, there was a distinct fillip in the progress of the societal position of homosexually-identified people in Australia. A justice of the High Court 'came out' himself and proclaimed homosexual oppression as a fundamental human rights issue in our country, the chief of a state police force marched in support of her lesbian and gay officers in the Mardi Gras parade, a major Christian church ruled that *practising* homosexuals were welcome in its ministry and a male/male couple featured, as 'just another couple', in a hugely popular television programme on home renovation.

What is interesting is that all of these phenomena appear to have resulted wholly from identity-based thinking. There is little that is Queer about the writings of his honour Justice Kirby, or the deliberations of the Uniting Church or the personae of 'the boys' from *The Block* (except, perhaps, in so far as manual work might be seen as transgressive practice by some gay men).

Most recently, and to some extent in parallel with progressive change in society at large, the increasing political influence of the 'Christian<sup>\*</sup> Right' in Australia and the United States, but not, interestingly, some other Western nations like Canada, has swung the pendulum back towards governmental oppression of people of sexual difference.

During the long run up to the 2004 Australian Federal Election, the Howard Government introduced and, with the acquiescence of the Labor Party, succeeded in enacting what the recently-retired Chief Justice of the Family Court of Australia, Hon. Alastair Nicholson AO RFD, has called 'one of the most shameful pieces of legislation that has ever been passed by the Australian Parliament'.(Nicholson, 2004, NPN)

<sup>&</sup>lt;sup>\*</sup> The use of the word 'Christian' to describe religious fundamentalists throughout the thesis should not be taken to imply that the author believes that the policy positions of such political groups in any way resemble the teachings of Jesus of Nazareth who, if he existed, seems to have espoused collectivist, inclusive, left wing positions on most issues.

He was referring to the *Marriage Amendment Act 2004*, which received viceregal assent and became part of the Law of Australia on 16<sup>th</sup> August, 2004. Justice Nicholson went on to say that the *Act*:

was clearly intended by the Howard Government to constitute a pitch to the religious right and mirrored a similar attempt in the United States introduced by President George Bush for the same purpose. ... The reason for its success [also] reflects no credit on the Latham Opposition, which abandoned principle for pragmatism rather than hand an election issue to the Government.(Nicholson, 2004, NPN)

The Marriage Amendment Act 2004 amends the Marriage Act 1961 to add a

definition of 'marriage' to the 'interpretation' list in subsection 5(1):

"marriage" means the union of a man and a woman to the exclusion of all others, voluntarily entered into for life,(Marriage Amendment Act 2004, Schedule 1,)

and specifically exclude 'certain unions' from recognition as marriage in Australia:

A union solemnised in a foreign country between:

(a) a man and another man; or

(b) a woman and another woman;

must not be recognised as a marriage in Australia. (Marriage Amendment Act 2004, Schedule 1,)

When the Attorney-General, Philip Ruddock, introduced the legislation into the Parliament on May 27<sup>th</sup>, 2004, he said that it was necessary:

because there is significant community concern about the possible erosion of the institution of marriage. The parliament has an opportunity to act quickly to allay these concerns. ... The government has decided to take steps to reinforce the basis of this fundamental institution.(Ruddock, 2004, p 29356)

Others have suggested that the need to 'act quickly' was more related to the impending election. The Member for Freemantle, Carmen Lawrence (who like the rest of her party ended up voting for the legislation) suggested in her Second Reading speech that the introduction legislation was 'a very political act' and that it was:

not about protecting the institution of marriage. As I understand it, there is no suggestion in the law that it is under challenge ... [but rather] ... I have no difficulty at all in seeing this as just another form of 'divide and conquer'. You [the Howard Government] sow the seeds of bias, prejudice and discrimination out in the community, just scatter them around a bit, and then allow them to grow for your political benefit. It is a very nasty tactic.(Lawrence, 2004, p 30724)

Senator Brian Greig, of the Australian Democrats argued that the announcement of the legislation 'on the eve of a pending election' demonstrated the government's intention to:

use the issue as an election wedge to target a minority, unsettle Labor and corral conservative voters. Gay marriage has sailed into this election much like the *Tampa* did in 2001.(Grieg, 2004, pp 26507-26508)

While Shadow Attorney-General Nicola Roxon (who also ultimately voted to support the bill) observed that in having the legislation introduced, the Prime Minister:

wanted to make a symbolic statement about his family values rather than put money or much needed support into families who might otherwise be worthy of his attention in upholding his ideas of family values. Yet all he is effectively doing with this bill is spelling out what is already part of the law in a gesture that was crafted to offend members of the gay and lesbian community.(Roxon, 2004, p 30508)

And there is no doubt that if this were indeed the Federal Government's intention, it has been successful in that aim.

In the run up to the Second Reading debate on the legislation in the Senate, on August 4<sup>th</sup> 2004, a rally 'organised by the National Marriage Coalition, composed of the Australian Christian Lobby, Australian Family Association and the Fatherhood Foundation' took place in the Great Hall of the Australian Parliament at the invitation of coalition senators.(Wallace, 2004, p 1) The forum was addressed by the Prime Minister and by Shadow Attorney-general, Nicola Roxon who, despite her earlier observations quoted above, announced to the Forum that Labor would support the legislation. Jim Wallace AM, Executive Chairman of the Australian Christian Lobby said in a press release the following day that 'the Marriage Forum was a sign of a seachange in politics and that Christians were increasingly finding their voice'.(Wallace, 2004, p 1).

The then leader of the Australian Democrats, Senator Andrew Bartlett, mentioned this Forum in his Second Reading Speech, which was broadcast on parliamentary radio. His voice breaking with emotion, he said of the legislation:

the impact of these sorts of measures, let alone giving them priority and urgency, involves a lot more than a little change to the law, because it reinforces signals and it gives legitimacy to the sorts of statements that were made by people last week in the Great Hall of our Parliament House. Some of them said that gay people were moral terrorists, they had vile passions, they were a sign of the moral decay of our society ... I still cannot get over my fury at walking into that meeting in the centre of our Parliament House ... (Bartlett, 2004, p 26535)

It must be said that the question of marriage is much contested within gay communities. Some hold the opinion that marriage is a flawed institution and that a campaign to make it available to same sex couples would be 'the wrong fight to have'. But the symbolic significance of the *Marriage Amendment Act 2004* as a declaration that, as Carmen Lawrence put it, gay and lesbian relationships are:

effectively second-rate relationships, that they are to be seen as unworthy in some respect and not to be accorded the respect that [the] parliament gives to people who are in a married relationship[,](Lawrence, 2004, p 30724)

should not be discounted.

At the recent *Health in Difference 5* conference in Melbourne, John Egan presented early results of a comparative ethnographic study of young gayidentifying men in Sydney and Vancouver. He reported, to quote his abstract, that 'the ideas of justice (and a just society) and democracy proved to be particularly compelling'.(Egan, 2005, p 18) He found that '[m]embers of the Sydney cohort feel less valued as queer men' and pointed in his presentation to legislative changes like the *Marriage Amendment Act 2004*, as well as experience of homophobia in schools, as among the reasons they cited for this perception, especially in contrast to their 'awareness of queer-friendly shifts in policy/discourse overseas'. 'Conversely', he argued:

the Vancouver members feel increasingly valued, though aware that support for them as queer men isn't universal. Increased anti-bullying and anti-homophobia education in secondary school and the recent legalization of same-sex marriage in British Columbia were cited as reasons for this optimism.(Egan, 2005, p 18)

Egan also found a greater sense of well being among the young men in Vancouver in association with this sense of being valued.

In an as yet unpublished recent study of attendees at Adelaide gay and lesbian community events late in 2004, by the author, 131 (57%) of 231 respondents to a question about the three 'social factors that have the greatest effect on the health and wellbeing of lesbian, gay, bisexual, transgender and intersex South Australians' nominated 'discrimination under the law' from a list of fifteen possible candidates.

The relationship between *personal* experience of discrimination and health outcomes is now reasonably well established (see Krieger for an excellent review (Krieger, 2000)). There appears, however, to be very little published research that specifically and directly examines the links between general societal and political oppression of *a group*, isolated from its economic impact, in a contemporary Western setting and its health consequences.<sup>\*</sup> The publication of Egan's work is awaited with interest and, sadly, the trajectory of public policy suggests that there may be an increasing need for further work in this area into the future.

# Sexual attraction, orientation, identity and behaviour

Any attempt to consider health inequity in relation to sexual diversity needs to be very clear about exactly what is being compared with a health outcome. The modern construction of 'the homosexual' conceals enormous diversity of attraction, identification and behaviour that needs to be considered if meaningful health equity conclusions are to be drawn.

<sup>&</sup>lt;sup>\*</sup> Jesdale and Zierler's paper on teenage suicide is the exception (see page 167). In addition, McKee has examined the impact of *positive* media portrayals of gay characters on the self-esteem of young gay men (see page 123)

Foucault argued (see page 118) that before the late Nineteenth Century a human could do things (like sodomy or buggery, or lying 'with mankind, as with womankind', Traditional, ND, verse 22) and experience things (like 'the love that dare not speak its name' Douglas, 1894)<sup>\*</sup> but could not *be* something (a 'homosexual').

As has been discussed (see page 124), the evidence for subcultures of same sex attracted people in Britain much earlier rather undermines this view. Further, Mohr has suggested that Foucault 'performed an intellectual sleight-of-hand' that meant that all he actually said was that 'the modern homosexual is the modern homosexual'. This may be true but is no more interesting or important than to say that 'there were no opera queens before 1598' (when the first opera was written).(Mohr, 1992, p 239)

None the less, the differentiation between 'being' and 'doing' remains salient to this discussion and introduces the concept of 'identity'.

# Sexual identity

Frable suggests that identity is 'the individual's psychological relationship to particular social category systems' and, in a perspective that is particularly apt in the case of people of sexual diversity, notes that it is also:

the term most often invoked by those who struggle to create meaning and purpose when culturally significant, ideologically powerful social category systems clash with personal and collective group member experiences.(Frable, 1997, p 139)

The earliest use of the word in this way in English appears to date from the Seventeenth Century (Simpson, 2005) but it seems to have gained currency in psychological discourse the 1960s.

Adam points out that there have been 'two major traditions' in the sexual identity literature. They might be termed the normative development discourse and the social identity discourse.(Adam, 2000, p 325)

<sup>&</sup>lt;sup>\*</sup> Though Lord Alfred Douglas actually wrote this line in 1894, 25 years *after* Kertbeny coined the term 'homosexual'

The first, which sprang from the study of developmental psychology originated by Piaget, has focused on the 'coming out' process and has generally proposed normative stages of identity development. As Cox and Gallois point out, 'these perspectives conceptualize the tasks facing the individual homosexual as being primarily about adjustment in a generally hostile environment'.(Cox *et al.*, 1996, p 1)

The most notable contribution in this stream is that of West Australian psychologist Vivienne Cass. Cass proposed a six stage model of gay identity development that she went on to validate with prospective studies.(Cass, 1984) The stages can be summarised as:

- 1. Identity Confusion (Who am I?)
- 2. Identity Comparison (I am different, could I be gay?)
- 3. Identity Tolerance (I am probably gay and I can put up with that)
- 4. Identity Acceptance (*I am gay and that's OK*)
- 5. Identity Pride (I am gay and you'd better get used to it!)
- 6. Identity Synthesis (*My gayness is just one part of me*)

Cass' work has been followed by a number of other schemata, and it has been recognised that the individual development of a gay identity does not always proceed in an orderly sequence, but this mode of thought about identity formation in people of sexual diversity has proven useful in the counselling setting in particular.(Davies, 1996) A contemporary reading of Cass' work gives rise to some discomfort about the politics of the idealised endpoint in her developmental sequence. The position of 'Identity synthesis' might be seen to imply passive and uncritical assimilation into, and thus complicity with, an oppressive societal system. For many, this would not be a desirable condition and would certainly not be seen as developmental goal.

Troiden, in a critique of Cass' work, pointed to the second, sociologicallyoriented, 'major tradition' when he posited that identity refers to 'organised sets of characteristics an individual perceives as definitively representing the self in relation to a social situation (real or imagined)' and that when an individual is removed from the setting that activates it, the relevant identity 'may become dormant'.(Troiden, 1985, p 102-103) He argued for the use of the term 'selfconcept' for the collection of many identities each of which is activated in particular social settings.

Cox and Gallois argue for the application of 'social identity theory', which they describe as 'concerned with social influences in the development of self-concept and the derivation of self esteem contingent upon it'.(Cox *et al.*, 1996, p 10) They describe:

two underlying processes in the theory. The first is self-categorization, from which we develop a number of social identities. Second in the process of social comparison, which aims at the enhancement of self-esteem. (Cox *et al.*, 1996, p 10)

They explain that categorisation is a general human cognitive strategy to make sense of the extreme complexity of the external and internal worlds and that categorisation of the self is an application of this technique. Self-categorisation as having the characteristics of a shared social group (a social 'identity' in Troiden's sense of the word) begins with an act of labelling but this is followed by 'an adoption over time of the normative (prototypical) behaviours, characteristics, and values associated with the particular group'. (Cox *et al.*, 1996, p 11)

They argue that:

the result of such self-categorization is that us/them dichotomies are formed, such as 'We are gay (and therefore have certain characteristics, norms and behaviours), and they are straight (and therefore have characteristics, norms and behaviours which we view as being of lesser value).'(Cox *et al.*, 1996, p 11)

Avid subscription to this belief system corresponds to elements from Cass' 'Identity Pride' stage. Everyone's self concept, Cox and Gallois contend, includes multiple identities (such as white, gay, male, GP) and their impact on self esteem is related to 'reactions to one of the group memberships from people in the others'.(Cox *et al.*, 1996, pp 11-12)

A man with social identities including gay and police officer, for example, might experience negative impacts on self esteem if there were a lack of acceptance of his gay identity in the social group of 'police officers', especially if there were also a negative appraisal of police officers among members of his 'gay' social group.

Under this model, some social identities will be in definite conflict with each other, such as 'gay' and 'Christian fundamentalist', with norms and values that are fundamentally incompatible. According to Cox and Gallois, this would necessitate 'some kind of resolution of the identities by the individual concerned'.(Cox *et al.*, 1996, p 12)

In settings where a social identity is particularly salient, they contend, the 'group membership norms and values are highly accessible'. Interactions with those outside the group will tend to be based on 'viewing others and oneself primarily from the position of the relevant group memberships, as opposed to [as] individual people'. In this setting differences between members of the group ('intragroup' differences) 'are minimized, while intergroup differences are maximized'.(Cox *et al.*, 1996, p 12)

In addition to these social identities, social identity theory also postulates the idea of 'personal identity', which refers to 'those aspects, behaviours, traits, and values individuals see as characterizing themselves as distinct from other individuals'.(Cox *et al.*, 1996, p 12) This identity, or identities, are most prominent in individual interpersonal interactions.

According to Cox and Gallois, self-esteem is then dependent on an evaluative process, social comparison. People gain high self-esteem if both aspects of their self-concept are perceived positively by others. One's social identities are evaluated against other social groups and 'people chose dimensions upon which they can compare favorably to others'.(Cox *et al.*, 1996, p 13) Thus the social group of 'heterosexual families' might choose the characteristic of unassisted reproduction and compare themselves favourably with gay and lesbian households. As Cox and Gallois put it:

[t]he result of such a social comparison, whether it is based on fact or not, is that heterosexuals not only see themselves as distinct from homosexuals, but better than homosexuals. That is, heterosexuals achieve not only distinctiveness, but *positive* distinctiveness.(Cox *et al.*, 1996, p 13, original emphasis)

They postulate that personal identity is evaluated in the same way against other individuals, often as 'in-group' comparisons against others who share a social identity. Thus, in the struggle for self-esteem in the face of disapproval by other groups, a gay identified man may choose the dimension of 'muscular definition', observe himself and other gay-identified men at a gymnasium, and gain positive distinctiveness in his personal identity if he compares favourably with other members of his own group.

The importance of between group evaluation under this schema stems from the ability of dominant groups (such as 'males', 'whites' or 'heterosexuals') to exert greater power in society. Thus they:

are in the position of being able to control the status quo. Social groups thus jostle for position ... with members of dominant groups attempting to maintain a status quo which is favorable to them, and subordinate groups attempting to alter the status quo in some way, so as to get a more favorable outcome for themselves. Social identity theory at a macro level, therefore, is about groups in conflict.(Cox *et al.*, 1996, p 13-14)

Cox and Gallois go on to point out that, in reality, social comparison with regard to characteristics like 'sex', 'race' and 'sexual orientation' does not generally proceed from direct experience but rather from the formation within a society of *stereotypes* about, for example, 'what a male or female is, what a homosexual and a heterosexual is'. They suggest that what is learned through this process reflects 'historical relations between groups in conflict' and 'becomes imbued with strong evaluative connotations'.(Cox *et al.*, 1996, p 14)

Social identity theory also postulates two groups of strategies by which members of non-dominant groups attempt to gain positive self-identity. The first of these is 'social mobility', whereby a person attempts to enter the dominant group through techniques like 'passing<sup>*r*</sup> that leave 'the comparative evaluation of the two groups unchanged' both in the general sense and in the evaluation of the individual trying to 'pass'.(Cox *et al.*, 1996, p 18)

<sup>&</sup>lt;sup>\*</sup> Allowing others to believe mistakenly that one is a 'white' person with dark skin, for example, or heterosexual.

The second group of strategies is 'social change'. These include 'social creativity' strategies where 'group members cognitively restructure the intergroup relationship' (by believing that gays are more 'artistic', for example, or cognitively denigrating heterosexuals as 'breeders') and 'social competition' which actually aims to change the power relationship between groups through actions like street marches and political activity.(Cox *et al.*, 1996, pp 18-19)

It can be seen that the two approaches to understanding sexual identity formation (the developmental discourse and social theories) are aligned with (though not exactly congruent with) the two major approaches to understanding sexuality, namely essentialism and constructionism (see p 124 above).

# Sexual 'orientation'

This term appears to have crystallised in the 1960s and seems to have been an attempt at non-judgemental categorisation of sexual identity. The original meaning of 'orientation' is geographical. Its first definition in the *Oxford English Dictionary* is '[t]he placing or position of a church, house, tomb, or other structure relative to the points of the compass, or other specified points'.(Simpson, 2005, NPN) Thus one can imagine, after Kinsey, 'exclusive' heterosexuality at the easterly compass point and 'exclusive' homosexuality at the westerly, with each individual geographically situated between the two.

The problems with the expression are its implication of fixity (that a person has a formed and stable 'sexual orientation' throughout life) and its reductionism (the suggestion that elements as complex and multifaceted as sexual attraction, identity and behaviour can be represented along a single axis).

None the less, the term is now well established, enshrined in law in many jurisdictions and has utility particularly in the pursuit of the rights of people of sexual diversity.

# **Sexual behaviour**

The extraordinary complexity surrounding the classification and selfclassification of people of sexual diversity has led some workers to focus only on sexual behaviour as a basis for description and investigation. This approach has been particularly pertinent in the study and prevention of HIV and other sexually transmitted infections since acquisition of these conditions is wholly related to what one does rather than what one is.

This focus has led to the creation of categories such as 'Men Who Have Sex With Men' (usually abbreviated to 'MSM'), which seems to have been coined in Australia in 1991,(Connell *et al.*, 1991) and has since gained currency worldwide.

Purely behavioural descriptions have the apparent advantage of precision of definition, but problems arise even here. The first is the definition of 'sex' itself. Would a man who is only ever masturbated by other men be described as MSM, or would sexual reciprocity or some form of penetrative sexual contact (such as fellatio) be required? The second is a temporal question. Would a man who had anal intercourse with a school friend on a single occasion in his teens be considered an MSM or would such a label require recent or recurrent sexual activity? Equally, would a gay-identified man who, with advancing age, has stopped having sex with other people all together still be an MSM? Thirdly the definition of 'men' causes problems. Would, for example, a sixteen year of male who is having sex regularly with other males of his own age, or with older men, be MSM? What about a person who was born male but now lives with a female gender identity?

There is also a problem about the limitation of the apparently-inclusive label of MSM by some workers to encompass only *non*-gay-identifying homosexually-active men, as in the phrase 'gay men and MSM'.

Finally, some gay activists have argued that the use of MSM as a focus around which to organise HIV prevention efforts is 'un-gaying' and denies the importance of mobilisation of a 'gay community', in accordance with Alma Ata principles, for the success of projects.(Frasca, 1998, NPN)

# Sexual attraction

Young people of sexual diversity are the focus of particular concern with regard to some serious aspects of health inequity such as suicidality. This has led to the observation that the traditional ways of categorising people are particularly problematic in this group.

Categorisation on the basis of identity would be likely to exclude young people who are to some extent aware of attraction to individuals of their own sex but have not yet formed any clear social identity in this regard or are struggling to retain membership of the dominant social identity group of 'heterosexuals' in spite of it. The stress of such struggles might render them among the young people most at risk of suicide.

Equally, classification on the basis of sexual behaviour would exclude people who have strong attraction to members of their own sex, and might even identify as gay, but have not yet become sexually active.

These problems with usual categorisations are most obvious when considering young people but might equally apply to people who are heterosexually married then recognise attraction to people of their own sex later in life.

For these reasons it has been suggested that 'same sex attracted' may be a better term by which to define populations of interest. The obvious difficulty of this, however, is that it refers to the wholly internal experience of attraction, which, by definition, precludes objective ascertainment. This leads to the consideration of compound ideas like 'males who identify as being same sex attracted', with an ever increasing likelihood for misunderstanding and misclassification.

#### Terminology in this thesis

In the light of the foregoing, no universal schema of 'classification of gayness' is employed in this thesis. Instead, an attempt is made to use clear terms to describe the concept under discussion at the time. Most often the term 'gayidentified' will be used when self-defined identity is the characteristic of concern and 'homosexually active' will be used for behavioural descriptions. Where general consideration is being given to all people whose sexual desire or behaviour transcends narrow societal norms, the concept of 'sexual diversity' will be invoked.

For simplicity, when the concerns of both gay-identified and other homosexually active men but not other people of sexual diversity are to be discussed, such as in the title of the thesis, the more inclusive term 'homosexually active men' will be employed. It is recognised that this shorthand form tends to silence the concerns of gay identified and same sex attracted males who are not currently sexually active, and the reader is asked to bear the concerns of these groups in mind deliberately throughout.

# An ethical consideration of sexual diversity

The notion of the 'oppression' of people of sexual diversity is central to the arguments of this thesis. Much of this oppression stems from individual belief or institutional doctrine that 'other-than-heterosexual' sexual behaviour is in some way 'wrong'. Thus it is pertinent to examine the foundations of this moral position. To fail to do so would leave the way open for comparison of the negative treatment of non-heterosexuals with such treatment for other 'wrong-doers'. Thus, for the members of the Christian Right who have the ears of our parliamentarians (see page 111), to speak of the 'oppression of homosexuals' would be like speaking of the 'oppression of murderers'.

Oppression is, according to the applicable definition in the *Oxford English Dictionary*:

[p]rolonged cruel or unjust treatment or exercise of authority, control, or power; tyranny; exploitation'.(Simpson, 2005, NPN)

The key requirement in this definition would seem to be 'cruel or unjust' and the 'or' in this phrase deserves initial comment. The dichotomy created by 'or' implies that (prolonged) 'cruel' treatment is always oppression whether or not it is unjust. Thus it would be correct to speak of the 'oppression of murderers' if one meant, for example, repeatedly pulling out their fingernails as part of a corrections programme. But the dichotomy also implies that 'prolonged ... unjust' treatment is oppression even when it is not especially 'cruel'. Thus the 'prolonged' imprisonment of murderers is not oppression because it is considered just (and not unreasonably 'cruel'). It follows that lifelong (though perhaps intermittent) negative treatment and 'exercise of power' over people of sexual diversity (provided it isn't sufficiently severe as to be dubbed 'cruel') is only oppression if it is also 'unjust'. Thus, if oppression relies on injustice, an exploration of whether sexual diversity is 'wrong', like murder, and thus of whether negative treatment on the basis of such diversity is just, is apposite.

The *Oxford English Dictionary* offers two applicable definitions (among several) for the word 'wrong' used adjectivally, namely:

A. II. 3. a. Of actions, etc.: Deviating from equity, justice, or goodness; not morally right or equitable; unjust, perverse

and

A. II. 5. a. Not in conformity with some standard, rule, or principle; deviating from that which is correct or proper; contrary to, at variance with, what one approves or regards as right.(Simpson, 2005, NPN)

These definitions are interestingly telling of the two principal ways of looking at issues of right and wrong in Western thought.

The first points to a philosophical tradition of morality (or, more precisely, ethics) whereby decisions about the rightness and wrongness of actions are subject to various forms of reasoned analysis.

The second invokes approaches that call on some external prescription for the intrinsic goodness of some actions and badness of others. The most obvious examples of this approach are religious codes and the most influential of these in the West has been the Judaeo-Christian tradition.

Each of these broad approaches can be scrutinised for their soundness (which is itself, of course, a form of rightness – ethical analysis creates interesting reasoning circles) but different methods are required to assess each. Philosophical considerations of morality can be subjected to examination for the logic of their conclusions but the application of prescribed codes is, by definition, arbitrary and the only analysis possible is to look at whether those codes have been faithfully translated from their origins to contemporary representations.

# An ethics of sexual diversity

Ethics is `[t]he science of morals; the department of study concerned with the principles of human duty'.(Simpson, 2005, NPN) It is concerned with a *reasoned* basis for describing actions or behaviour as `right' or `wrong'. There have been two major schools of thought through the history of ethics, utilitarianism and deontology, and it is interesting to see how each plays out in a consideration of sexual diversity.

#### A utilitarian analysis of sexual diversity

Although it has been argued that they stem from ideas that go back as far as the pre-Socratic Greek philosopher Parmenides, the principles of Utilitarianism were first proposed by Jeremy Bentham in the Eighteenth Century and were more fully developed by John Stuart Mill in the Nineteenth.(Anonymous, 2004c) Utilitarianism is a consequentialist approach. It posits that the rightness or wrongness of an action is determined wholly by its consequences. It argues that to determine whether an action is right one performs a mental calculation of the amount of benefit and the amount of harm that will result from the action and relies on the result of this calculation for moral guidance. As Beauchamp puts it, utilitarians 'regard an action or practice as right if it leads to the greatest possible balance of good consequences or to the least possible balance of bad consequences'.(Beauchamp, 1999, p 27) The most obvious criticism of the approach is, of course, that it simply moves that question of good and bad (or right and wrong) up a level of argument because it still requires an assessment of what are 'good' and 'bad' consequences. Generally, though, utilitarian reasoning relies on relatively uncontroversial definitions for this purpose like good meaning 'maximising human happiness' and bad meaning 'maximising human suffering'. The final requirement for a utilitarian analysis would seem to be impartiality, that is that 'all parties affected must receive equal and impartial consideration'. (Beauchamp, 1999, p 28)

For a utilitarian analysis of sexual diversity, an idealised chain of events will be considered where two 'single' biological male Australian persons meet, are attracted to each other, spend time together and then have fully consensual and mutually satisfying anal sex, in private, using condoms.

First it is necessary to assess the benefits of such a chain of events for all of those involved. The most obvious benefit to the two men in question is that it brings them pleasure and probably happiness. The attraction that each can see on the part of the other boosts the sense of self worth of each, the human interaction they experience may be engaging and stimulating, and the physical activity brings them both physical pleasure and sexual satisfaction.
Another benefit for the men involved is the mitigation of harms or discomforts that they might otherwise experience such as loneliness and sexual frustration. The sense of wellbeing generated might even (it will be argued) reduce their risk of mental ill-health or improve their productivity at work with benefits for human society more generally.

It is then necessary to consider the potential harms that might result for all who are involved. On first glance these are hard to find. It might be argued that the sexual encounter carries a risk that one participant might pass a sexually transmitted infection to the other. This is clearly mitigated by the use of a condom but not eliminated altogether. The people who live next door might argue that seeing the men arrive together late at night, and surmising that they might be having sexual activity that they find unpleasant to think about, is harmful to them. It might also be argued that by meeting and having sex with each other, the men are 'choosing' not to begin a heterosexual relationship that night that might lead (hopefully much later) to procreation and the intrinsic goods of parenthood like the propagation of the species and the pleasure that child-rearing brings.

None of these arguments stands up to close scrutiny, however. The risk of sexually transmitted infection transmission is not related materially to the genders of the individuals involved. Although HIV is much more prevalent among males in Australia, globally it is most frequently transmitted heterosexually, and infections such as genital herpes are spread just as easily between males and females as between people of the same gender. The concentration of HIV among males in Australia could even be taken to argue for women having sex with each other rather than with men. So it can be seen that the possible harm of infection transmission may argue against sex altogether but certainly doesn't argue against homosexual activity specifically.

The nosy neighbours may experience displeasure or even revulsion, but are they really 'involved' in the sense that utilitarianism requires? If they are, then the extent of their 'involvement' (that is very peripherally) must surely bear on the balancing and relegate their concerns to a small effect compared with the strong benefits to the men involved. The neighbours have also contributed to the ill effects they report feeling by actively scrutinising the activities of their neighbour and his sexual partner.

The argument related to procreation actually relates not to the homosexual encounter itself but rather to the lack of a potentially procreative heterosexual encounter. Thus any single person who stays home on the same evening will have produced the same harm. So, clearly, would a married person who knew himself or herself to be sterile but who engaged in a heterosexual activity with a spouse on that evening in preference to encouraging the spouse to take another, fertile, partner.

Thus it can be seen that utilitarian analysis appears to argue for the 'rightness' of the scenario discussed. More complex balancing might be required for consideration of an anonymous encounter in a park, or of a sadomasochistic exchange, but in any of these scenarios, whatever other arguments can be mounted, it seems unlikely that the genders of the people involved would be a decisive factor.

#### A deontological analysis of sexual diversity

The other major stream in the science of ethics is deontology. This approach focuses on notions of moral duty and is largely attributed to Immanuel Kant who wrote about morality in the late Eighteenth Century. Deontology argues against the contingency of the utilitarian view whereby it is possible to do wrong things (like lying) for right reasons (like sparing someone distress). For a deontologist, some things are always, intrinsically, wrong, a view that Kant called 'the categorical imperative'.(Beauchamp, 1999, p 29)

This imperative has been argued in two major ways that some have suggested are actually deductively equivalent. The first is the notion of 'Universal Law', which essentially says that something is wrong if it cannot be consistently true for everyone.

Roberts neatly illustrates this idea with a familiar narrative:

Suppose you are weary of taking notes. You think to yourself, "Why should I take notes when there are others who take excellent notes. They are good-hearted students or suckers. All I have to do is before the exam, ask to borrow their notes, copy them, and I'm in great shape. So, I just sit back enjoy the lectures or skip class for that matter, then borrow their notes. I'm a winner."

Now let's convert your individual proposed action to a maxim (a general rule of behavior). The maxim is, "Never take notes, always borrow another student's notes." Universalize that maxim to be practiced by all persons for all times and what happens? No student takes any notes, and, consequently, there are no notes to borrow. So, were everyone to obey the maxim, it would not work. It is irrational to command a maxim which cannot work (remember, the saying ought implies can. If something is claimed to be a duty, it is at least possible that it can be done). But, there would be no notes to borrow if every student failed to take notes and obeyed the maxim. Self-defeating maxims involve internal contradictions in that they are impossible to perform when universalized.(Roberts, 2005, NPN)

The second way that this can be argued is through the notion of 'humanity', which is usually summarised as '[o]ne must act to treat every person as an end and never as a means only'.(Beauchamp, 1999 29) Thus, Kant argued, one should never deny the humanity or personhood of another but treating the person *only* as a means to one's own ends. This view holds that each human has intrinsic and unconditional value as an 'autonomous rational agent' and that this value does not derive from the opinions or actions of others.(Roberts, 2005) Thus, if a person is used only as a means to an end, the person doing so regards something (someone) of unconditional value as having only conditional value (as a means to his end). It is argued that this is like 'regarding a square as having the properties of a circle', and is thus logically contradictory.(Roberts, 2005, NPN)

Roberts again offers a clear narrative to illustrate the approach and underline its equivalence with the notion of logical contradiction that underlies the first formulation.

He speaks of borrowing money with the promise of repayment, then failing to repay the loan, which has been forgotten by the lender:

When I break my promise, I am treating the lender merely as a means to my desired ends; I am using him and his money merely as a means to obtain the things I want. But, suppose I were the lender. Would I be willing to be treated in such a manner? Not on your life. So, the contradiction is revealed when we see that we are willing to do something to another person, which action we would not be willing to have done to us. If the rule is to be universalized, then it has to apply to us. But, if we are not willing to be governed by the rule, although we are willing to apply the rule to others, universalization does not occur. What happens is that we use other persons merely as means. And that involves a flat-out contradiction.(Roberts, 2005, NPN)

The example of the same sex romantic encounter introduced on page 144 can now be considered in deontological terms. In this analysis it is necessary to seek the maxim(s) that the narrative implies so that they may be interrogated for contradiction through the formulations of universality and humanity. The rule might be that if two people of the same sex are attracted to each other and otherwise unencumbered they may, if they wish, have a romantic interaction including sexual activity. An attempt to universalise the rule does not seem to be problematic. If such a course of action were available to everyone (given the provisos in the scenario) there is not intrinsic contradiction.

It is important to appreciate that the maxim here is not 'only have sex with people of the same gender', or even 'have sex with people of the same gender to the exclusion of people of the opposite gender', but rather 'have sex with people of the same gender if you want to and there is no other reason not to'. Thus spurious universalisation arguments like Prime Minister Howard's famous suggestion that gay marriage would somehow threaten '... the continuation of the species' do not apply.[Howard, 2003 #484\@, NPN]

It is not impossible for the right the scenario implies to be available equally to everyone. Similarly, there is nothing in this scenario or implied maxim that appears to treat anyone only as a means to the ends of another. Each of the parties is consenting, enjoys aspects of the personhood of the other and is mutually benefited.

The rules would have to be re-examined in the face of more a complex sexual diversity story but, again, it seems unlikely that either the universality or humanity test would turn in any analysis merely on the genders of the people involved.

The position of the nosey neighbours in the story, however, produces an interesting result under deontological analysis, especially if it is imagined that they are moved by their displeasure to daub 'poofters deserve AIDS' on the side of their neighbour's car – as some such people have in Australia in living memory.

They would appear to argue that 'if I see evidence that makes me believe you are doing something that I personally find distasteful it is acceptable for me to denigrate you and damage your property'. The test of universalisation yields a result that is not actually impossible but is certainly curious. It would confer on the men in the story, for example, an equivalent right to daub 'breeders are bigots' on the car of the nosey neighbours and would appear to undermine the principle of privacy completely. The humanity test also leads to an intriguing outcome. Since the nosey neighbours are treating the men in the story not as individual humans but as abstract and stereotypical 'poofters', in the service of their own (im)moral crusade, it might be argued that they are in fact treating the men as a means to their end.

#### A health ethics analysis of sexual diversity

In addition to the two 'classical' threads in ethics, other approaches such as 'virtue ethics' (what would a good person think?), 'the ethics of care' (what would feel right if this were a close relationship with another particular human being?) and 'casuistry' (what scenarios can I imagine that might help me to make the right decision about this matter?) have had proponents and detractors in the science of ethics.

In the ethics of health and health care, moral deliberations are often grouped into four principles suggested by Beauchamp and Childress:

- 1. respect for autonomy (respecting the decision-making capacities of autonomous persons)
- 2. nonmaleficence (avoiding the causation of harm)
- 3. beneficence (providing benefits and balancing benefits against risks)
- justice (fairness in the distribution of benefits and risks).(Beauchamp, 1999, p 33)

Through this framework it is easy to argue in favour of freedom for people of sexual diversity (their activities are their own business (autonomy), harm noone (nonmaleficence), prevent sexual frustration and loneliness (beneficence) and are – or should be – available to anyone who wants them).

It is very hard to argue for heterosexist prohibition, which appears to do the opposite (intrudes on autonomy, causes the harms of oppression, frustration, isolation and self-hatred, fails to benefit the people involved – at least in terms to which they would autonomously subscribe – and appears arbitrary and unjust).

### Prescribed codes of sexual behaviour

As was argued above (see page 143) moral approaches that rely on prescribed codes, such as the Judeo-Christian tradition or Q'ranic law cannot be usefully subjected to internal analysis since they are definitionally arbitrary.

Paragraph 2357 of the Catechism of the Catholic Church, for example, declares that:

Homosexuality refers to relations between men or between women who experience an exclusive or predominant sexual attraction toward persons of the same sex. It has taken a great variety of forms through the centuries and in different cultures. Its psychological genesis remains largely unexplained. Basing itself on Sacred Scripture, which presents homosexual acts as acts of grave depravity, tradition has always declared that "homosexual acts are intrinsically disordered." They are contrary to the natural law. They close the sexual act to the gift of life. They do not proceed from a genuine affective and sexual complementarity. Under no circumstances can they be approved.(Catholic Church, 1997, NPN)

The main justification for the last sentence of this paragraph appears to be 'Sacred scripture' and 'tradition'. The further arguments toward the end of the paragraph appear to be quasi-philosophical justifications for this dogma, but are easily subject to logical refutation. The appeal to 'natural law' fails to specify quite what it means, but the appearance of homosexual behaviour in no less than 450 non-human animal species would seem *prima facie* to refute it.(Bagemihl, 1999) The argument about procreation has been considered above (see page 146) and the supposed absence of a potential for 'a genuine affective and sexual complementarity' in homosexual interaction would seem to be denied by the many loving gay and lesbian relationships that continue for very extended periods.

Arbitrary codes like the Catholic catechism can, however, be interrogated for their origins and decisions made about their validity in the light of this knowledge. The late John Boswell in his colossal *Christianity, Social Tolerance and Homosexuality* traced the origins of antipathy toward homosexuality in the Catholic church and found that it came not from scripture – which can be read to prohibit many activities, such as charging interest on loans, that are fully condoned by the contemporary church – but rather from the political history of Europe between the fall of the Roman Empire and the Thirteenth Century CE.(Boswell, 1980) He observed that:

[t]he early Christian church does not appear to have opposed homosexual behavior per se. The most influential Christian literature was moot on the issue; no prominent writers seen to have considered homosexual attraction "un-natural," and those who objected to physical expression of homosexual feelings generally did so on the basis of considerations unrelated to the teachings of Jesus or his early followers. ... Moral theology through the twelfth century treated homosexuality as at worst comparable with heterosexual fornication but more often remained silent on the issue. ... Homosexual passions ... were celebrated in spiritual as well as carnal contexts.[Boswell, 1980 #386\@, p 333]

#### But then:

[b]eginning roughly in the latter half of the twelfth century, however, a more virulent hostility appeared in popular literature and eventually spread to theological and legal writings as well. The causes of this change cannot be adequately explained, but there were probably closely related to the general increase in intolerance of minority groups apparent in the ecclesiastical and secular institutions throughout the thirteenth and fourteenth centuries. [Boswell, 1980 #386\@, p 334]

Prescribed codes can also be examined for their consistency with philosophically derived ethical positions. The discussion of sexual diversity already undertaken indicates that any prohibition of mutually-consenting same sex activity in arbitrary codes appears to be inconsistent with most philosophically derived conclusions.

# The health characteristics of homosexually active men

In this section, the literature on the prevalence of particular health problems in homosexually active or gay-identified men, relative to that in other men, will be critically surveyed. Since the literature in this area is large, the review will focus on the following health characteristics, chosen because of their prominence and their significance to the general health status of homosexually active men:

- 1. Mortality
- 2. Suicidality
- 3. Depressive disorders
- 4. Anxiety disorders
- 5. Report of childhood sexual abuse
- 6. Substance use

The search strategy for this literature review utilised three electronic databases: Medline (PubMed), PsychINFO and Sociological Abstracts. The specific health topics were searched in conjunction, through an 'AND' operator, with the terms 'gay', 'homosex\*', and 'MSM', as well as the MeSH term 'homosexuality' where appropriate. This was augmented by hand searching the reference lists of papers identified in the primary search. Only studies reported since the birth of gay liberation at the Stonewall riots in 1969 (see page 122) were included. More than 1500 papers were examined. Inclusions and exclusions for each category are discussed in the text.

## Mortality

Mortality and life expectancy are generally considered to be the most important markers of the health status of a population, but there appears to have been extraordinarily little credible investigation of these outcomes among people of sexual diversity.

As far as can be determined, data related to sexual identity, attraction or behaviour have not been collected in general population data or in death or disease registers in any jurisdiction to date, although New Zealand is actively considering such a question in its 2006 Census.(Statistics New Zealand, 2005)

The inclusion of Indigenous status in such whole population data collection, in comparison, has enabled the extent of the mortality inequality experienced by Indigenous Australians to be meaningfully quantified. It is acknowledged that ascertainment of Indigenous status in death registers is incomplete and Indigenous people are consequently undercounted. Nonetheless, the Australian Bureau of Statistics has determined that the age-specific death rate for Indigenous people was higher than that of other Australians at all ages, and 'between the ages of 30 and 64 years the death rates of Indigenous Australians were around seven times the rates for the total population in those age groups'.(Australian Bureau of Statistics, 2003, NPN)

In the absence of such whole population data identifying people of sexual diversity, only much less satisfactory methods are available to estimate relative mortality.

Another complicating issue in this area is the profound impact of HIV disease on mortality among the populations it has affected, including homosexually active men in Australia. While this mortality is clearly extremely important, its high levels make the identification of mortality inequality due to mechanisms other than HIV very difficult to discern.

Consideration of this factor is rendered still more complex by the marked changes in the mortality effects of HIV on homosexually active male populations over time. Palella's group demonstrated a two-thirds reduction in mortality among people with HIV in the United States between 1995 and 1997, following the introduction of combination antiviral therapy.(Palella *et al.*, 1998) Given that more than 80% of Australians notified with HIV are homosexually active males, it could be expected that the similar treatment effect observed in Australia would also have had a dramatic effect on the mortality of homosexually active men overall here.

Among the very few studies that have tried to look at relative mortality between homosexually active men and other groups in Western countries, two principal methodologies have been employed: cohort studies and demographic modelling.

Perhaps the most important cohort study was reported by Koblin and colleagues in 1992.(Koblin et al., 1992) They followed a cohort of 8906 selfidentified 'homosexual men' recruited through gay clinics, gay organisations, bath houses and 'mobile vans sent to areas of the city where large numbers of homosexual men resided' for hepatitis B serology studies in 1977-1978.(Koblin et al., 1992, p 647) The cohort included 7095 white men, whose mortality over the ten years from 1978 to 1988 was compared with the mortality of agematched white males the United States generally. 773 deaths were observed among white men in Koblin's cohort, yielding a raw death rate of 773/7095/10 years = 10.3 per thousand per annum. Compared with a predicted 208 deaths based on the matched population rates, this yields Standardised Mortality Ratio (SMR) of 3.7 with a 95% confidence interval of 3.4 – 3.9. Interestingly, when relative rates were calculated for each year, the standardised mortality rate in the first year of follow up (1978) was significantly *lower* than that predicted for the age matched population. This most likely represents an artefact due to the exclusion of people who were not well enough to have been recruited.

The rate was then not significantly different from that in the general population between 1979 and 1982 and the first significant difference was seen in 1983. Rates then remained significantly higher than predicted thereafter, peaking in 1987 at a standardised mortality ratio of about 8 (this is shown only graphically in the paper), before appearing to fall a little in 1988. No change was seen in the rate of deaths attributable to non-AIDS-related causes over that ten years of follow up. Given that AIDS-related mortality was zero in 1978 and 1979, when cohort mortality was no higher than that among age matched US males, the data suggest that all of the excess mortality over the follow up period for this study was related to HIV disease.

Hessol and colleagues, in a paper also published in 1992, reported a similar analysis of the outcomes in a cohort of 6704 'homosexual and bisexual men recruited between 1978 and 1980 from the municipal sexually transmitted disease clinic' in San Francisco, again for the purpose of hepatitis B studies.(Hessol *et al.*, 1992, p 561) 1518 members of the cohort (23%) had died by 1990 yielding an average annual death rate of 1518/6704/13 years = 17.4 per thousand per annum. Again comparison was undertaken with US mortality figures but in this paper neither details of calculations nor overall SMRs were included, and only specific SMRs for particular causes of death were used to describe the results. In 1987, the methodology showed a specific SMR for HIV infection and immune disorders of 154 (95%CI: 131 – 179) but also showed a specific SMR for suicide of 3.4 (95%CI: 1.1 –7.9).

Ndimbie and colleagues, in a 1994 paper, examined the death rate in a cohort of 1115 homosexually- and bisexually-identified men who volunteered between 1984 and 1987 to be part of a prospective study of the natural history of AIDS.(Ndimbie *et al.*, 1994) At the time of analysis in 1990, 377 (34%) of the men were HIV positive. 90 deaths occurred among this cohort over the six years of the study. Deaths in the age range 20 – 44 were compared with the overall death rate in this age range in the county in which most of the participants resided. Raw numbers included in the paper allow *post hoc* calculation of annual death rates.

As would be expected in the late 80's among a group where about a third was HIV infected, the raw death rate in the cohort was much higher than men of similar age in the general community from which it was drawn (83/861 participants/6 years = 16.067 per thousand per year, compared with 343 deaths per year in a population of 222,347 = 1.54 per thousand per year; OR for death over six years = 11.5, 95%CI: 9.14 to 14.5). For non-AIDS causes of death only, the rate in the cohort was 13/861/6 years = 2.52 per thousand per year. AIDS and non-AIDS deaths for the county generally were not differentiated in the paper. Thus what can be said is that the rate of non-AIDS deaths in the cohort appeared to be somewhat higher than the *total* death rate among men of a similar age generally in the county from which the cohort was recruited.

For sudden unexpected death, the respective rates were 0.968 per thousand per year (5/861/6 years) for men in the cohort and 0.688 per thousand per year (153 per year/222,347) in the general community. This is not a significant difference (OR for death over six years = 1.41, 95%CI: 0.583 to 3.40), but the number of sudden unexpected deaths in the cohort was small.

One other paper is worthy of mention, which used modelling techniques and population data to estimate the impact of HIV disease on the mortality of Canadian 'gay and bisexual men'.(Hogg *et al.*, 1997, p 657) This study is important because it has been taken up widely by right wing organisations in the United States such as the 'National Association for Research and Therapy of Homosexuality',(Melonakos, 2005) and the 'Family Research Council',(Dailey, 2005) to argue for the 'negative health effects of homosexuality'. In response to what they saw as misuse of their research, the authors were moved to write specifically to the *International Journal of Epidemiology*, which published the original study, to disassociate themselves from the conclusions drawn by such organisations.

What Hogg and colleagues actually did was to construct demographic models of male mortality and life expectancy for residents of Vancouver, British Columbia. They used three possible rates for the proportion of males aged twenty or older who were 'gay or bisexual', namely 3%, 6% and 9%.(Hogg et al., 1997, p 658) Non-HIV deaths were then distributed in the model on the basis of these rate assumptions. Then, based on Canadian epidemiology, it was assumed that 95% of known HIV deaths during the study period (1987 to 1992) occurred among 'gay and bisexual men' and this was applied to the model. On the basis of these assumptions, they modelled the age specific death rates and life expectancies for 'gay and bisexual' men in Vancouver aged 20 at the time of the study. Because of the way the model worked, the lower the assumed 'prevalence' of being 'gay or bisexual', the larger the estimated difference in life expectancy for those who were, since the deaths were 'distributed' among fewer people. On this basis Hogg's group calculated that the death rate for men aged 40-44 might be as much as ten times the rate for all men in that age group (based on the 3% assumption) and the life expectancy for a 20 year old as short as 34.0 years.

The authors of this study had intended to demonstrate the devastation that the community of 'gay and bisexual' men was expected to experience as the result of HIV infection and they succeeded, graphically, in doing so.

Their study method was sound but history has shown that their model made a major assumption that, fortunately, turned out to be wrong. They appear to have assumed that the death rate from HIV would be constant through the projected life span of the men they were modelling. This was understandable at the time when the paper was written (it was accepted for publication in October 1996) since the dramatic impact of antiviral therapy on AIDS mortality was still in the process of being observed. As already mentioned, Pallela's group reported in 1998 that the mortality of people with HIV in the United States fell by two-thirds between 1995 and 1997.(Palella *et al.*, 1998) This phenomenon has been seen throughout the Western world and is echoed by Australian data that show that the raw number of deaths of people with after an AIDS diagnosis fell from a peak of 753 in 1994 to 91 in 2002.(McDonald, 2003)

There is no doubt that this change would have a profound impact on the mortality predictions that Hogg's group made and that, even under the 'worst' of their three models, life expectancy for 'gay and bisexual' Vancouverian men would now be much better than they predicted.

This historical development also highlights a major concern, not about Hogg's paper itself, but about the way that it has been used. Their research method was population modelling and they sought to look only at the likely effects (as it seemed at the time) of HIV on a population. They actually *assumed* that the death rate from non-HIV causes would be the same for 'gay and bisexual' men as for other men in Vancouver. Despite their being very clear about this, commentators since have (mis-)used their work to suggest that it points to 'homosexuality' as a 'cause' of early mortality.

Dailey, for example, in a paper on the website of the 'Family Research Council' dated '2005', suggests under the heading of 'reduced life span' that the Hogg article concluded that 'homosexuals ... have a significantly reduced life expectancy'.(Dailey, 2005, NPN) He then tries to support this position by guoting directly from Hogg's paper:

*If the same pattern of mortality* were to continue, we estimate that nearly half of gay and bisexual men currently aged twenty years will not reach their sixty-fifth birthday.(Hogg *et al.*, 1997, p 657, emphasis added)

In fact, the same pattern of mortality has quite clearly not continued and any academic who claims expertise in this area (as Dailey does, despite his PhD from Marquette University being in Religion rather than a biological or social science) cannot have failed to be aware of this. The presentation of a modelling paper as if its speculations were an established finding, eight years after it became clear that a critical assumption of the model had proven false, is nothing short of academic fraud.

Nonetheless, the paper has been used in this way by no less than 20 further, apparently different, religious and political organisations identified from just the first five pages<sup>\*</sup> of a 'Google' search of the World Wide Web on March 28<sup>th</sup> 2005 using the criteria 'Hogg homosexual mortality',(Google, 2005) namely:

- 1. Catholic Standard and Times(Brinkman, ND)
- 2. Concerned Women for America(Concerned Women for America, 2005)
- 3. Reasons to Believe(Deem, 2004)
- 4. National Association for Research & Therapy of Homosexuality(Nicolosi, 2004)
- 5. Center for Reclaiming America (Centre for Reclaiming America, 2002)
- 6. Emmaus(Fox, ND)
- 7. Christian Answers.Net(Lamont, 2004b)
- 8. HeartTouches.Com(Edmiston, 2002)
- 9. Canada Family Action Coalition(Canada Family Action Coalition, 2005)
- 10. Real Women of Canada(Real Women of Canada, 2004)
- 11. Coalition for Marriage(Coalition for Marriage, 2004)
- 12. Renewal Ministries(Renewal Ministries, 2004)
- 13. Answers in Genesis(Lamont, 2004a)
- 14. Letros Com Garfos(Nuttall, 2004)
- 15. LifeSite(LifeSite, 2004)
- 16. Anglican Mainstream(Vonholdt, 2003)
- 17. Pure Love Club(Pure Love Club, 2003)
- 18. Liberty Online(Standish, 2004)
- 19. Prison Fellowship(Colson, 2003)
- 20. International Organisation of Heterosexual Rights(International Organization of Heterosexual Rights, 2005)

Perhaps most disturbing, is that this search also identified a similar use by the American College of Pediatricians in a review on gay parenting dated 'January 22, 2004'.(American College of Pediatricians, 2004)

Before leaving the literature on mortality among people of sexual diversity, it is worth a passing mention of the output of Paul Cameron's group at the so-called 'Family Research Institute' in Colorado, US. Their paper 'Does homosexual activity shorten life?', published in *Psychological Reports*, is also often quoted on conservative websites.(Cameron *et al.*, 1998)

<sup>\*</sup> After which the author's fortitude gave out.

This paper used a range of different methods in an attempt to verify the hypothesis that 'adoption of the homosexual lifestyle' is associated with a shorter life span. It firstly tracked the age of people whose obituaries appeared in the *Washington Blade* gay newspaper and concluded that the median age at death of the subjects of these reports between 1993 and 1997 was 39. It then noted that among 187 obituaries for people who died from a non-AIDS cause reported in the same period, '[f]orty-five (4%) were the result of accidents, murder or suicide'.(Cameron *et al.*, 1998, p 850) The paper then makes a completely invalid comparison, saying '[i]n contrast, each year in the U.S. about 0.1% of men aged 25-54 die violent deaths' and quoting a National Center for Health Statistics document.

Fortunately, this report is still available on the World Wide Web.(National Center for Health Statistics, 1997) When it is examined the Cameron group's obfuscation is apparent. They appear to have added up the prevalence of the three causes of violent death listed in the document (motor accident, homicide and execution, and suicide) for this age group and presented this as the comparator. What they fail to point out is that these prevalences are calculated with the number of *living* people in the appropriate age group as the denominator. Even if the obituaries technique had complete or representative ascertainment of gay deaths (and it almost certainly doesn't) Cameron and colleagues have calculated a rate of violent death *as a proportion of deaths.* Thus comparison with national death rates, calculated as a proportion of (living) population, is either deliberately misleading or astonishingly incompetent.

It is remarkable that this error was not identified in the peer review process for the article and this raises serious doubts about the integrity of this procedure at *Psychological Reports* at the time the paper appeared.

Cameron's group repeats the comparison technique a few lines later to imply (erroneously) that gay obituary subjects were also much more likely to have died of heart disease than Americans aged 45-54 years generally (though why a different [false] comparison age range was chosen for this parameter is left unremarked).

From there, the paper goes on to draw doubtful conclusions from a published population survey of sexual behaviour, same sex registered partnership data from Scandinavia (where it suggests that the younger age of people marrying and divorcing same sex compared with different sex partners implies a shorter life expectancy) and Colorado state HIV testing data.

In the end, the paper draws conclusions that are soft, but probably not soft enough, for the poor quality of the analysis:

The four lines of evidence we have examined point in the same direction. Neither individually nor collectively do they definitively indicate the median age of death for those who regularly engage in homosexual activity is less than age 50, but they certainly *tilt* toward that conclusion.(Cameron *et al.*, 1998, p 864, original emphasis)

There is nothing soft about the extrapolation they go on to make, however, despite the lack of evidentiary support:

As indexed by lifespan, homosexual activity appears to be slightly "less unhealthy" than intravenous drug abuse but substantially "worse" that smoking, exposure to asbestos, or any number of activities and substances that currently garner public opprobrium.(Cameron *et al.*, 1998, p 865)

Earlier papers from Paul Cameron's group, including their first publication based on gay obituaries, (Cameron *et al.*, 1994) have been subject to erudite and strident criticism by Gregory Herek from the Psychology Department of the University of California, Davis. (Herek, 2005) Herek also points out that Cameron was expelled from both the American Psychological Association<sup>\*</sup> and the Nebraska Psychological Association in 1984 and has never been readmitted. Further, Herek reports that in 1985 the American Sociological Association was also moved to disassociate itself from Dr Cameron after he had been described in media reports as 'a sociologist'.

<sup>\*</sup> Though Cameron argues on his own website that he 'resigned'.(Cameron, 1994)

Despite the absence of scientific rigour in the Cameron group's output, its occasional appearance in so-called 'peer reviewed' journals, some of which are even Medline listed, (eg Cameron, 2002;, 2005; Cameron *et al.*, 1996a;, 1996b) lends credence and an air of authority to countless quotations like the following from H.A. 'Buster' Dobbs (who describes himself as 'a preacher' at Klein Area Church in Houston, Texas, US):

According to a recent study ... the average age of men dying from AIDS is 39. The average of homosexuals dying from all other causes is 41 (Paul Cameron, William I. Payfair<sup>\*</sup>, and Stephen Wellum, The Homosexual Lifestyle, Family Research Institute, Inc., Washington, D.C., 1992). Homosexuals are detestably filthy, repulsive, loathsome, and odious. They are morally bankrupt. Their behavior is sickening. They are wholly lacking in ethics. They are deranged and dopey.(Dobbs, ND, NPN)

#### **Summary**

Since relevant characteristics have not been collected in census data or death registries in any jurisdiction, accurate conclusions cannot be drawn about the relative mortality or life expectancy of people of sexual diversity. The small number of methodologically-sound studies undertaken reveal that it is likely that the mortality of homosexually active men in Western countries was markedly increased by HIV infection between the mid 1980s and the mid 1990s. This excess mortality seems to have abated considerably since the introduction of combination antiretroviral therapy for HIV in 1996.

No meaningful data have been available to date on which to draw conclusions about the relative mortality of homosexually men on the basis of causes of death other than HIV infection, except possibly a higher rate of death by suicide in Hessol's study.(Hessol *et al.*, 1992)

The absence of knowledge on this question has not stopped groups who see same sex behaviour as morally wrong, and seek to justify this position by couching 'homosexuality' as a voluntarily embarked upon 'unhealthy behaviour', from misusing legitimate studies and promulgating the conclusions of scientifically dubious investigations to further their political ends. In so doing, they contribute further to the stigmatisation and consequent health inequity under examination in this thesis.

<sup>&</sup>lt;sup>\*</sup> Sic. The author to whom Rev Dobbs refers is actually William <u>L Play</u>fair.

### Suicidality

There is a considerable literature on the subject of suicidality among people of sexual diversity.

While very few studies have looked at completed suicide, many have examined suicidal ideation and reported history of ('unsuccessful') suicide attempt. Many have measured prevalences of these variables among convenience samples of gay-identified people, while a smaller number have looked at population samples and compared prevalences for gay-identified or homosexually active people with those for people with only heterosexual experience. Most papers have looked at male and female prevalences while some have concentrated on males alone. The majority of investigation has concerned adolescents and young adults. A small number of studies have been conducted in Australia.

### Completed suicide

Only a few studies that attempt to look specifically in any detail at the relationship between 'sexual orientation' and completed suicide were found in the literature. Two used the technique of 'psychological autopsy' where the lives of people who are believed to have suicided are investigated retrospectively. The third looked at the rate of sudden unexpected death in a large cohort of gay men over a ten-year period. The fourth study used the novel technique of examining raw suicide rates of non-Hispanic white males aged 11 to 18 in comparison with enactment by their state of residence of antidiscrimination laws related to 'sexual orientation'. An additional psychological autopsy study found high rates of completed suicide in people with AIDS in New York in 1985, among whom the majority were gay men.(Marzuk *et al.*, 1988)

Rich and coworkers looked at 13 men who 'by history had predominantly or exclusively homosexual relationships and considered themselves to be homosexual' among 202 adult men who were thought to have suicided in San Diego in the United States in a twenty month period in 1981 to 1983.(Rich *et al.*, 1986, p 450) This yields a raw rate of 6.4% of suiciding men who could be identified as gay, which approximates to the prevalence of 'homosexual orientation' among males in many studies in the English-speaking developed world. If this could be relied on, it would argue for a prevalence of completed suicide among gay men that is no different from other men in this community.

There are several significant problems with this study, however. The first is that only men who were thought by the informants interviewed ('family members, spouses, acquaintances, employers, other witnesses, physicians and other professionals') to have 'considered themselves homosexual' were 'counted' among the thirteen. The report indicates that there were homosexually-active men - though we are not told how many - who were counted as heterosexual 'because of expressed preference for heterosexual activity'.(Rich *et al.*, 1986, p 450) Especially given that this study was undertaken in the 1980s, it seems very likely that this would result in marked underestimation of the proportion of men who were, in fact, gay-identified or at least same sex attracted. It is axiomatic that some of the gay men who suicided might have been uncomfortable with their orientation and may have concealed it from the informants. Particularly where informants were spouses or employers this effect would have been expected to be very likely.

The second major problem with this study concerns the age range of the homosexual men identified. The study appeared to consider only men age 21 or over who had suicided. This would exclude younger males who were homosexually active or same sex attracted, whom the other suicidality literature suggests are at high risk of suicide attempt. Five of the 13 gay suiciders were under 25, which suggests that this study truncated the age distribution of gay suicide in the middle of one of its peaks. Further, it is of interest that there were no homosexually-identified men among the 83 men who suicided at age 43 or over.

This seems very surprising from first principles and suggests that ascertainment of sexual orientation in the older age group was even less accurate than in the remainder of the cohort. The thirteen suiciding gay men, then, were in fact drawn from a sample of 119 suiciding men aged 21 to 42, yielding a raw proportion of men who were gay-identified of 11%, which is above the majority of recent estimates for males in general Western communities.

These factors taken together suggest that the conclusion of Rich's group that the study 'adds support to the conclusion that gays do not have a higher suicide rate than straights' is not supported.(Rich *et al.*, 1986 p 453) Indeed the results appear to be exactly what might be predicted if the limiting factors described above were operating in a population where gay men were suiciding at a significantly higher rate than heterosexuals.

Shaffer's group, on the other hand, examined the histories of people who had suicided in the New York area, aged less than twenty years, in a two-year period from 1984 to 1986.(Shaffer *et al.*, 1995)

170 people in that age group were found by the Medical Examiner to have suicided during the period and the researchers were able to investigate 120 of them. Among the fifty not investigated, informants on nine could not be traced and those of the remaining 41 refused to answer questions. 95 of the investigated suiciders were males. In this study, the suiciders were compared with 147 randomly selected controls of the same age and from the same county. Three of the 95 investigated male adolescents were believed to have been homosexually active compared with none of the controls. This was not a significant difference, as might be expected with the small numbers.

This study, too, raises many questions. The first is the remarkable result that none of the controls was identified to have had homosexual experience. This is a surprising finding in any Western sample and suggests that the technique of face to face interview of informants used in this study is very insensitive at identifying homosexually active males.

This problem is so fundamental as to require that the study be discounted but the identification of even three homosexually-active suiciders by the technique suggests that true proportion who were same sex attracted may be much higher. In addition, it is not difficult to imagine that young gay-identified males who were estranged from, or in conflict with, their families might be overrepresented among the fifty suiciders who could not be investigated.

In addition to these specific studies, a few others have drawn conclusions about the relative rates of completed suicide in the course of other investigations. Hessol's paper for example, which is discussed in detail on page 155, found a specific standardised mortality ratio for suicide of 3.7 (95%CI: 1.1 - 7.9) in cohort of 'homosexual and bisexual' men in San Francisco, compared with population data, in 1987.(Hessol *et al.*, 1992)

In Ndimbie's 1994 paper, also discussed on page 155, only one of the six 'sudden unexplained deaths' in a cohort of 1014 'homosexual and bisexual men' was definitely determined to be suicidal by the country coroner but three of the other four were drug overdoses that were judged either 'accidental' or 'undetermined' and the last one was a vehicular accident.(Ndimbie et al., 1994, p 248) They report that 45% of deaths in this age range in the county in question at this time 'were due to accident, suicide or homicide' and 'suicides constitute 40% of these deaths'. Thus 18% ('40% of 45%') or 62 of the 343 annual deaths would be expected to have been suicidal yielding an incidence of 62/222,347 = 0.279 per thousand per year. If only one of the cohort deaths were indeed suicide, the rate would be 1/861/6 years = 0.194 per thousand per year. If, on the other hand, all of the drug overdose deaths were actually suicide, the rate would be 4/861/6 years = 0.774 per thousand per year, or more than 2.5 times the expected rate. Thus it can be seen that this analysis is highly susceptible to variation in the classification of sudden unexpected deaths by the coroner.

It is also quite surprising that in this study there were no sudden unexpected deaths among 'AIDS patients', since the rate of suicide among people with clinical AIDS in Marzuk's study was very high.(Marzuk *et al.*, 1988)

This raises the question of whether a proportion of the people classified as having died of AIDS may in fact have suicided but since their deaths were not 'unexpected' they missed capture. Further it may be that approaching mortality from AIDS may have prevented the playing out of suicidality in some of these men who might otherwise have done so during this period.

Indeed it is a difficulty with all of the studies of completed suicide that the definition of suicide used is an official finding by the district coroner or medical examiner. Such findings may well underestimate the rate of suicide in young men who die suddenly in one-person car crashes, apparent firearm mishaps and drug overdoses that are thought to be accidental. It seems likely that same sex attracted men who have hidden their sexual identities from their families might also be more likely to attempt to conceal their suicides and chose methods where their deaths might be thought to be accidental.

Jesdale and Zierler attempted to overcome the difficulty of ascertainment of sexual identity and attraction by studying the effects on overall adolescent suicide rates of legislation that might be expected to have a specific effect on the wellbeing of same sex attracted young people. (Jesdale et al., 2002) They used publicly-available suicide and census data on fourteen US states for the period 1990-1999 and compared this to their history of enactment of 'legislation to protect the rights of gay, lesbian and bisexual people'.(Jesdale et al., 2002, p 62) They hypothesised that the enactment of such legislation would be a marker for an improvement in the social position of people of sexual diversity in the community, which might be associated with improved well being and reduced suicide risk among same sex attracted young people. In doing so they relied on the belief (first proposed by Gibson in 1989 US Department of Health and Human Services, 2000, pp 3-110) that issues related to same sex attraction were important in completed suicide often enough that a significant change in this area would have a measurable impact on the overall rate of suicide among young people (particularly males). They also recognised, however, that the enactment of gay rights legislation might also be a more general marker for a more accepting and 'kinder' society that might be less likely to induce a suicidal response in adolescents regardless of sexual attraction.

Rates of adolescent suicide were compared between states that had enacted such legislation and those that had not, as well as 'before and after' rates within states that enacted such legislation during the study period. They confined the analysis to non-Hispanic white males 'to reduce confounding effects across states' of 'gender, racial classification and Hispanic ethnicity', while ensuring large enough cell sizes for statistical validity.(Jesdale *et al.*, 2002, pp 62-63)

The study found that, almost without exception, states with gay rights legislation had lower rates of suicide among non-Hispanic white boys aged 11-18 during the study period. The annual rate among such boys living in a jurisdiction without such legislative protection was 101.4 per million boy-years, while that among boys living under such legislation was 72.3 per million boy-years. This 'reduction' of 29.1 per million boy-years had quite a narrow 95% confidence interval of 24.5 – 33.7 suicides per million boy-years and is quite striking in its magnitude. When states that had enacted legislation during the study period were compared in a 'years before versus years after' manner, a reduction of 19.7 suicides per million boy-years was seen (with a 95%CI of 11.0 - 28.4 per million boy-years). It would be expected that this reduction would be smaller than the difference between states with and without established laws, since the debate that leads up to the enactment of laws would itself have been expected to have a 'protective' effect in some of the 'before years'.

The authors attempted to control for other possible causes such as the general trend towards a reduction in youth suicide rate in all states and the age distribution of boys within the 11-18 range in each state but this did not change the overall result. They also conducted separate before and after analyses for each state that enacted legislation during the study period and found that, with one exception, the general relationship held, though the cell sizes were smaller and the results less statistically robust.

The one exception was the state of Maine where gay rights legislation was enacted and repealed during the study period (and then reinstated and again repealed after the end of the study in 2000) as a result of local political shifts. It is not surprising that this environment of controversy with, no doubt, vocal contributions from reactionary political forces, was *not* related to a reduction in youth suicide.

The most recent contribution to the literature on sexual orientation and completed suicide is a paper from Qin, Agerbo and Mortensen who examined the complete dataset of all 21,169 people who were recorded as having committed suicide in Denmark between 1981 and 1997 and compared it with the characteristics of aged matched controls from the Danish population database who did not suicide.(Qin et al., 2003) From 1994 on, Denmark has had a system of legal registration of same sex relationships and so membership in such a relationship could be compared between the group who suicided during this period and the controls. On this analysis, people in such a relationship had a 4.31 odds ratio of having suicided (95%CI: 2.23 - 8.36) compared with the rest of the population. In a multivariate model including other factors that predicted suicide, membership of a registered same sex relationship retained an odds ratio of 3.63 (95% CI: 1.71 - 7.67) and was the demographic variable most strongly associated with suiciders. Its effect was greater than being single (OR: 1.87), being an age pensioner (OR: 1.59), having been born in Greenland\* (OR: 2.65) or being in the lowest income quartile (OR: 2.66). Registered same sex partners partners were not separated by gender in this analysis but 65% of suiciders overall were male.

<sup>\*</sup> Greenlanders are a marginalised ethnic group in Danish society.

In considering these results it should be remembered that marriage and cohabitation generally have a protective effect against suicide (in this study single people had a significantly greater chance of being suiciders than heterosexually cohabiting people who again had a higher chance than married people). This would suggest that the group identified through their registered relationships would be expected to have been less likely to have suicided than uncoupled same sex attracted people (who could not be identified in the data). If this is true, it implies an association between same sex attraction generally and completed suicide that is even greater than that seen in this study.

#### Australian Studies

There do not appear to have been any published studies of completed suicide among sexual minorities in the Australian context.

#### Summary

Among a plethora of research on suicidality in homosexually-active men, the 'business end' of completed suicide has been surprisingly scantily studied until very recently. While it sometimes concluded from the earlier literature that the rate of actual suicide is no higher among gay men, there are serious limitations to these studies and their findings appear to be equally consistent with a higher rate. A study in the late 1980s found very high rates of suicide among people with AIDS, of whom the majority were gay men.(Marzuk et al., 1988) One innovative study found a clear relationship between overall suicide rates in non-Hispanic white adolescent males and failure to enact of gay rights legislation in US states.(Jesdale et al., 2002) Despite the importance of this finding, it could be explained by such legislation simply being a marker for a 'kinder' society. A recent study of all completed suicides in Denmark identified a strong relationship between this outcome and membership of a registered same sex couple, which as has been discussed, would expected to underestimate any association between suicide and same sex attraction due to the 'protective' effect of being coupled.(Qin et al., 2003) Thus it appears that the recent literature support a higher rate of suicide related to the social disadvantage of gay-identifed men. Further population studies are clearly required, however, to replicate the Danish findings in Australia and examine the relationship between sexual identity, social disadvantage and suicide more directly and more clearly.

#### Report of prior suicide attempt

Many studies since 1969 have measured the prevalence of reporting one or more prior (unsuccessful) suicide attempts among convenience samples of homosexually active people or, less often, population samples who were also asked about sexual identity, attraction or behaviour.

Saghir and coworkers, writing in 1970 ten years before the first appearance of AIDS, compared 89 self-identified 'male homosexuals' recruited from 'homophile organisations' with 35 unmarried heterosexual paid volunteers.(Saghir *et al.*, 1970, p 1079) Rates of report of ever attempting suicide were 6/89 (7%) among the gay men and 1/35 (3%) among the controls. This is not a significant difference on *post hoc* statistical analysis but its historical interest remains.

There appears to have been relatively little work in the area in the 1970s and 80s, though Bell and Weinberg reported, in their 1978 book *Homosexualities: a study of diversity among men and women*, a lifetime suicide attempt rate of 18% in a large sample (N = 683) of white gay-identified males interviewed in San Francisco in 1969-70, compared to 3% in 337 matched 'heterosexual' controls.(Bell *et al.*, 1978) The same data (compiled from interviews undertaken by the Kinsey Institute) were presented in a peer reviewed paper by Harry in 1983.(Harry, 1983) *Post hoc* analysis of these data using a 2x2 table yields an odds ratio of 7.40 (95%CI: 3.83 to 14.3, P < 0.0001 by Fisher's Exact Test [FET]) for the gay-identified men reporting a suicide attempt compared with the 'heterosexual' controls.

Flavin, in 1986, published three case reports of alcohol-dependent gayidentified men attempting to acquire HIV as an expression of suicidality.(Flavin *et al.*, 1986) Then in 1989, Schneider's group reported a study of 108 gayidentified males aged of 16 – 24 from college gay societies and 'rap groups' at a gay community centre.(Schneider *et al.*, 1989) The prevalence of reported suicide attempt was 19% among the college students and 23% at the community centre. Associated factors were concern about sexual orientation at a young age, paternal 'alcoholism' and, perhaps surprisingly, absence of a religious faith.

In 1991, Gary Remafedi and coworkers reported a study of 137 gay and bisexually-identified males aged 14 - 21 recruited through gay bars, gay social groups and advertisements in gay papers.(Remafedi *et al.*, 1991)

Among this group, 31% reported at least one prior suicide attempt. More than half of the attempters reported the use of 'moderate to high lethality methods' and one in five required hospitalization. Risk factors for suicide attempts in this group included gender atypicality, early self-identification as homosexual or bisexual, experience of sexual abuse and the use of illicit drugs.

In 1993, D'Augelli and Hershberger reported a study of 194 gay, lesbian and bisexually-identified people under twenty-one years, including 142 males, attending community centre programmes. They found that 42% reported a prior suicide attempt and there were 'no sex differences'.(D'Augelli *et al.*, 1993, p 425)

Predictors of prior attempt included 'feeling overwhelmed', higher depression and anxiety scores, non-disclosure to parents and lack of 'outness' more generally. Data from this study were also reported in two further papers with D'Augelli's colleague Scott Hershberger as lead author.(Hershberger *et al.*, 1995;, 1997)

Proctor and Groze in 1994 surveyed 221 people with a mean age of 18.5 involved in gay, lesbian and bisexual social groups, including 159 males.(Proctor *et al.*, 1994) Participants were mostly white and lived in the United States or Canada. 40% of the sample reported having previously attempted suicide but no gender breakdown was provided. Having attempted suicide was predicted by low self-esteem scores, lower school performance and poor perceived family support.

Given that non-whites in the general US community have higher levels of attempted suicide, Rotheram-Borus and collegues, in a 1994 study, were surprised to find similar rates to those reported by Procter among 138 mostly Hispanic and black gay and bisexual males with a mean age of 16.8 years attending a community based agency in New York.(Rotheram-Borus, 1994) 39% had attempted suicide. Of them, more than half had made more than one attempt and 14% had tried to kill themselves in the month prior to interview. In terms of life-stress, only gay-related stresses such as having their sexual preference discovered or disclosed predicted having attempted suicide. High levels of non-gay related stress were reported across the cohort but these were not related to suicidality.

In 1998 Waldo's group, in a study of gay vicitmisation, found lifetime rates of attempted suicide of 42% among 194 urban and 32% among 54 rural gay, lesbian and bisexual young people,(Waldo *et al.*, 1998) then in 1999 Safren and Heimberg compared 56 gay, lesbian and bisexually-identified 16 – 21 year olds (including 21 males) with 48 heterosexuals who were all taking part in after school programmes in Philadelphia.(Safren *et al.*, 1999) 30% of the sexual minority adolescents reported ever having attempted suicide compared with 13% of their heterosexual peers, which was a significant difference. Further, 58% of the gay, lesbian and bisexually-identified attempters recounted that they had 'really hoped to die' in the attempt compared with 33% of heterosexuals who reported a suicide attempt.

In one of the few papers on this topic from outside the Anglophone world, Cochand and Bovet published a study in 1998 of survey responses from 164 gay or bisexually-identified men in French-speaking Switzerland recruited by snowball techniques and through an HIV treatment centre.(Cochand *et al.*, 1998) The survey had a low response rate, with fewer than a third of distributed questionnaires returned. The age range of this sample was 22 – 66 with a median of 34. 23% of respondents reported at least one suicide attempt and the 65 HIV positive men did not differ significantly from the rest of the cohort in this measure.

All of the foregoing studies are subject to criticism because they used convenience samples of homosexually-identified or homosexually active people, who may not have been typical because of the way that they were recruited. Between 1997 and 1999, no less than six large population-based studies were published as if to address this concern. Bagley and Tremblay undertook the first published 'modern' population-based study when they delivered a computerised questionnaire to a stratified random sample of 750 males aged 18-27 in Calgary, Canada.(Bagley *et al.*, 1997) 13% of the sample were classified as gay or bisexual on the basis of either self-identification (11%) and/or current sexual activity (9%). 5 of 82 gay or bisexual men (6%) had made a 'serious' suicide attempt compared with 3 of the remaining 668 men (0.4%). Men designated gay or bisexual were 14 times more likely to have reported such an attempt than their heterosexual counterparts.

A significant difference was also seen with regard to less serious 'self-harm' behaviour which was reported by 13 of the 82 gay or bisexually designated men (16%) but only 37 of the 668 other men (6%).

At the beginning of 1998, Faulkner and Cranston reported results from an anonymous survey of a random sample of 3054 grade 9 to 12 students in 45 Massachusetts public high schools.(Faulkner *et al.*, 1998) The 105 students who reported same sex sexual experience were compared with the 1563 who reported only opposite sex sexual experience (the remainder had not been sexually active). 28% of the homosexually active students reported having attempted suicide in the prior 12 months, compared with 13% of the students who were only heterosexually active. This was reported to be a significant difference at the <0.05 level but the data were not broken down by gender in the report.

The largest study was reported by Remafedi's team in 1998.(Remafedi *et al.*, 1998) They examined health survey results from a cohort of 36,254 students in school grades 7 to 12 among whom 96% completed a question on sexual orientation. 184 males (and 152 females) described themselves as either bisexual or homosexually-oriented. This results in a surprisingly low prevalence of homosexual or bisexual identification of around 1%, but it should be remembered that people who were unsure of their sexual orientation were excluded from the group and this would be expected to be a significant proportion in a cohort of this age. The gay or bisexually identified respondents were compared with peers from the same school and class who did not identify in either of these ways. 28% of gay or bisexually identified males reported prior suicide attempts compared with 4% of their peers, resulting in an odds ratio of 7.10 (95%CI: 3.05 - 16.53) and this difference was significant with a probability level of <0.00001.

Garofalo's group looked at 3365 high school students (an 81% response rate out of a possible 4167) among whom 129 (3.8%) identified as gay, lesbian, bisexual or 'not sure'.(Garofalo *et al.*, 1999) Interestingly, only 55% of young people who reported same-sex sexual experiences identified as gay, lesbian, bisexual or 'not sure'.

This study asked about suicide attempts in the prior twelve months only. 31% of gay, lesbian, bisexual or 'not sure' respondents reported an attempt during that period compared with 9% of their peers and this difference was significant at the <0.001 probability level.

Lock and Steiner assessed 1769 high school students aged 12 - 18 (including 922 males) who completed an anonymous self-report survey.(Lock *et al.*, 1999) 55 (6%) of the males identified as gay or bisexual, while an additional 93 (10%) were unsure of their sexual orientation making a total of 148 (16%) of males who were gay, bisexual or 'not sure'. These respondents were found to be at significantly increased risk of a range of mental health problems on the Juvenile Wellness and Health Survey but the specific data on suicidality are difficult to discern in available versions of the paper.

Fergusson and coworkers, in New Zealand chose a rather different design when they examined data on a cohort of 1265 people (including 635 males) born in the same year in Christchurch, who were reviewed periodically during their adolescence.(Fergusson et al., 1999) At the age of 21, 1007 (80%) of the cohort answered questions about their 'sexual orientation'. 28 people (including 11 men) either identified as gay, lesbian or bisexual, or had reported a sexual relationship with a person of the same gender at some stage since age 16. This yields a rather low prevalence of 2% for this fairly broad definition of sexual diversity among the males, and may reflect cultural aspects of the South Island of New Zealand that mitigate against male disclosure of nonheterosexual identity and behaviour. Nonetheless, the results for prevalence of attempted suicide were remarkably consistent with the other population studies. 32% of homosexually active or attracted respondents reported at least one suicide attempt compared with 7% of the remainder of the cohort. This represents an odds ratio of 6.2 (95%CI: 2.7 - 14.3) and is statistically significant at the <0.001 probability level.

One further study published in 1999 warrants consideration because of its unique design. Herrell and coworkers used the Vietnam Era Twin Registry (n = 4774 pairs) to identify 103 pairs of male twins (48 pairs monozygotic and 55 pairs dizygotic) who were discordant for adult homosexual activity (that is, where one twin had had one or more male sexual partners after the age of 18 while his brother had not).(Herrell *et al.*, 1999) The average age of the cohort at the time of reporting appears to have been about 50 years.

15% of the homosexually active twins reported one or more suicide attempts compared with 4% of their exclusively heterosexual brothers, yielding an odds ratio of 6.5 (95%CI 1.5 – 28.8). This effect remained significant when differences in 'abuse' of alcohol or other drugs and in depressive symptoms were accounted for.

Since the flurry of research activity published in 1999, a few other relevant studies have appeared in the literature. Van Heeringen and Vincke from Belgium reported on a sample of 404 young people (including 208 males) aged 15-27 (mean 20.9) recruited from gay holiday camps and secondary school classes.(van Heeringen et al., 2000, p 495) 'Sexual orientation' was rated on a 10 point scale on the basis of the gender of reported sexual partners and, interestingly, the objects of their sexual fantasies. All of the people from the gay holiday camps were judged to be 'homosexual or bisexual' by this method as were four of the 189 recruited from school classes. 17% of the 'homosexual or bisexual' subjects reported a prior suicide attempt compared with 6% of the 'heterosexuals'. Unusually, the rates were significantly different in females (25% vs 6%, OR = 6.25, 95%CI: 2.35 - 16.65) but not for males (12% vs 6%, OR = 2.47, 95% CI: 0.78 - 7.81). The sample sizes in this study were relatively small but the difference in the size of the effect by gender is interesting since it is the reverse direction to differences seen in similar studies from Anglophone communities. This may reflect cultural differences in gendered performativity in countries with a British tradition and those without.

Cochran and Mays reported, in 2000, a large population based study, utilising data from an extension of the Third National Health and Nutrition Examination Survey, which was completed 3648 American men, aged 17 to 39, between 1988 and 1994.(Cochran *et al.*, 2000) Only 2% of men in the sample are said to have reported having any male sexual partners, and an additional 6% apparently reported no sexual partners at all. However, the authors have employed weighting techniques that are not explained in the paper and the exact derivation of these figures is not clear.

19% of homosexually active men reported having attempted suicide compared with 4% of exclusively-heterosexually-active men and 0.5% of celibate men. The value for homosexually active men was significantly higher, and that for celibate men significantly lower, than the result for exclusively-heterosexuallyactive men at the 0.05 probability level.

Another population study was reported by Blake's group in 2001.(Blake *et al.*, 2001) They found 151 gay, lesbian or bisexually-identified, and 55 'not sure' respondents among 4159 of 5370 grade 9 to 12 school students who completed a survey conducted as part of an evaluation of HIV education programmes in Massachusetts in 1995. This yields a prevalence of identification as gay, lesbian, bisexual or 'not sure' of 5%. 51% of the sample was male. 36% of gay, lesbian, bisexual or 'not sure' students reported having attempted suicide, compared with 9% of heterosexually-identified respondents. This difference was significant at the <0.001 probability level but no gender breakdown was included in the paper.

In 2001, Anthony D'Augelli's group at Pennsylvania State University published two further uncontrolled studies on the topic. One replicated many of the previous reports among a gay organisation survey sample of 350 gay, lesbian or bisexually-identified people aged 14 to 21 of whom 195 were male.(D'Augelli *et al.*, 2001b) The prevalence of attempted suicide among the males was 34%.

The other study was of interest because it investigated the other end of the age range and focused on 416 gay, lesbian or bisexually-identified adults age 60 – 91 years including 297 males.(D'Augelli *et al.*, 2001a) 52 people in this cohort (13%) reported a previous suicide attempt. By retrospective recall, about a third of these attempts were made before the age of 22, about two thirds between 22 and 59 and only 4% above the age of 60. No gender breakdown was provided for this variable but suicidal ideation did not appear to vary much between the sexes. These analyses suggest that, although there may be a peak in suicidality at or just before the age of 21, attempted suicide continues to be a concern throughout the adult life of gay men until old age.

Also in 2001, Russell and Joyner published data from the first data collection in the (US) National Longitudinal Adolescent Health Study.(Russell et al., 2001b) This survey used a purposive sampling and data weighting plan that aimed to be representative ('with respect to region of the country, degree of urbanization, school type, ethnicity, and school size', Russell et al., 2001b, p 1277) of all US students in grades 7 to 12, some 22 million individuals. 'More than 12,000 students' at 134 schools provided the primary data and, of these, 11,940 (including 5,686 males) provided 'complete information on adolescent sexual orientation and suicidality'.(Russell et al., 2001b, p 1277) They used a somewhat unusual method for identifying same sex attracted individuals that involved the questions 'have you ever had a romantic attraction to a male?' and 'have you ever had a romantic attraction to a female?' together with enquiries about the respondent's last three 'romantic relationships', including 'the sex of the romantic partner'. If any of these questions identified same sex 'romantic' attraction or partnership, the person was considered to have 'same-sex sexual orientation' for the purpose of the study.(Russell et al., 2001b, p 1277) Participants were also asked if they had attempted suicide (on one or more occasions) in the prior twelve months.

Using this definition, and with weighting of the results with regard to the characteristics described above in an attempt to represent all US high school students, Russell and Joyner found that 8.4% (95%CI: 7.5% - 9.3%) of males were same sex 'oriented'.

With regard to suicide attempt, 5.0% (95%CI: 3.0% - 6.9%) of same sex oriented males reported an attempt in the prior twelve months, compared with 2.0% (95%CI: 1.6% - 2.4%) of other males. Since the confidence intervals do not overlap, it can be seen that this more than two-fold difference was statistically significant.

In 2002, Gary Remafedi reported data on 255 males aged 15-25 (of 297 eligible subjects invited to participate) attending gay venues in Minneapolis/St Paul.(Remafedi, 2002) Only men who had been homosexually active in the prior twelve months were deemed eligible. 85 men (33%) reported having attempted suicide at some stage and 12 (5%) in the prior year. No heterosexually-identified comparison group was used.

Attempters were significantly more likely to be African-American, to be urban residents and to not be currently enrolled in an educational programme. This study, though somewhat 'old fashioned' in its methodology, is included because of its recency. It demonstrates a rate comparable with (but toward the upper end of the range of) those in similar convenience-sampled studies conducted in the 1990s.

Also in 2002, Mathy reported findings from an internet-based sexuality survey with 40,935 responses worldwide.(Mathy, 2002) Of these, 2,731 were excluded on the basis of 'a priori MMPI-like lie-detection items and exclusion of subjects with 100 percent scores on high or low self-attribution scales' (that are not further explained in the paper, Mathy, 2002, p 217) and a further 772 were excluded on the basis that they failed to identify a country of residence, checked 'none' for their 'sexual orientation' or were from Africa (which was excluded since fewer than five respondents identified as homosexual or bisexual), leaving 37,432 included responses. The study is presented as a comparison of the relationship between sexual identity and suicide rate 'on five continents' but the vast majority of respondents (34,843 or 93%) reported living in the United States.
Participants were recruited from visitors to an internet-based international news service, so no calculation of response rates was possible, and it is of interest that 82% of respondents worldwide were male. The proportion of male respondents who identified as 'homosexual' or 'bisexual' varied from 7% among the 388 men from Asia to 17% of the 204 men from Australasia, and the rate in the large US sample was 13%. The proportion of men reporting that they had ever 'made a serious suicide attempt or gesture' on each continent was as set out in Table 2.

Continent (n)	% of 'homosexual/ bisexual' males reporting suicide attempt	% of 'heterosexual males reporting suicide attempt	OR	95%CI
Asia (388)	10.7%	2.2%	5.3	1.3 - 21.4
Australasia (204)	17.1%	5.3%	3.7	1.2 - 11.1
Europe (445)	4.5%	3.1%	1.5	0.3 - 6.9
North America (29,406)	8.3%	3.8%	2.3	2.0 - 2.6
South America (178)	11.5%	2.0%	6.5	1.2 - 34.1
Total (30,621)	8.4%*	3.8%*	2.3*	2.1 - 2.7*

Table 2: Proportion of males with suicide attempt history.(Mathy, 2002)

(\* = calculated by author post hoc)

It can be seen that homosexual and bisexually-identifying males were significantly more likely to report a history of suicide attempt in all geographical regions except Europe. Even there the rate was higher, and it is quite possible that a larger sample would have yielded a significant difference.

It is interesting that, with the exception of the Australasian results, all of the absolute lifetime suicide attempt rates for homosexual and bisexually-identified men in Mathy's data (and indeed those for heterosexually-identified men) are lower than those in the other studies examined. This, together with the dramatic preponderance of males in the overall sample, suggests that respondents in this study have been selected from a substantially different population from the remainder of the research.

Recruitment through advertisements on an international news website might be expected to bias toward relatively socially advantaged and educated people (who might be more likely to have had access to the necessary technology and an interest in international affairs). Both social advantage and education levels are associated in other studies with lower suicide rates and so it would be unwise to treat Mathy's sample as generally representative.

The technique clearly selected for males (83% of all included respondents were male), which supports this concern about bias. As a result, Mathy's study is included for interest but will not be used to draw conclusions about the absolute lifetime rate of suicide attempt in populations of homosexually active men.

Later in 2002, Jay Paul and colleagues, from the University of California, San Francisco, published a large study based on interviews with 2,881 homosexually active men, aged 18 or over, in four US cities (Chicago, Los Angeles, New York & San Francisco).(Paul *et al.*, 2002) Although no non-homosexually-active comparison group was used, the interviewees were obtained by probability methods (random digit dialling and telephone enquiry about the presence of a homosexually active adult man in the household) in an attempt to avoid the sample biases associated with recruitment via groups or venues.

The participation rate was high (78%) among the 3700 'eligible households' so ascertained, but it would be expected that assessment of eligibility via an unsolicited telephone call to the member of a household who happened to answer would be a relatively insensitive technique. In a society where most unsolicited telephone calls represent unwelcome commercial spruiking and where privacy is increasingly valued, it would be expected that a high proportion of call answerers would be unprepared to divulge sensitive information. Further, many call answerers who were, for example, the parent, spouse or housemate of a homosexually active man might be unaware of this fact. It also seems likely that these effects could act in a systematic way to reduce the likelihood of recruiting those homosexually active males who are most secretive about their sexual activity because they are the most troubled about it and may be at greater risk of suicidal behaviour.

Despite these issues, the Paul study is interesting because of its large sample size and its investigation of co-factors. The overall rate of report of a prior suicide attempt among the 2881 homosexually active men was 12% and a rate of 30% was seen among the 3% of the sample who identified as Native American.

Higher rates were also seen in men who identified as 'bisexual' (16%) or has having 'other' sexual identity (21%). Report of a suicide attempt was significantly related to lower reported income, unemployment and not having been to 'college', as well as to parental substance problems, a history of childhood physical abuse and a history of childhood sexual coercion.

Also in 2002, McBeeStrayer and Rogers published a small study of 162 people of who self-identified as lesbian, gay or bisexual, including 85 men, sampled through health centres, groups and by snowball techniques. The paper's primary purpose was to investigate correlates of suicidal behaviour in terms of an 'existential-constructivist model'.(McBee-Strayer *et al.*, 2002, p 279) 24% of all participants reported a prior suicide attempt but this figure was not broken down by gender in the paper.

In 2003, a second New Zealand team reported data from a longitudinal birth cohort (see also discussion of Fergusson's paper on page 176). On this occasion, 1037 people who had been born in Dunedin in 1972-3 were the subject, and Skegg's group reported on the 946 people (including 480 males) for whom information about 'sexual orientation' and self harm behaviours was available at age 26.(Skegg *et al.*, 2003) This represented 93% of the surviving cohort.

Despite allusions to 'sexual orientation' in the title and text of this paper, the study was actually focused on same sex attraction since classification was based on the answers to questions about to members of which gender participants had been attracted 'ever' or 'these days'.

They were then divided into people with 'persistent major same-sex attraction' if they reported attraction to their own gender at least as much or more than to the opposite both 'ever' and 'these days' (8 males), or 'minor same-sex attraction' if they reported any attraction to their own gender in either question (a further 45 males).

33 of the 427 non-same-sex-attracted men (8%) reported a suicide attempt while nine of the 45 men with 'minor same sex attraction (20%) and two of the eight men with 'persistent major same sex attraction' reported this history. The paper reports a multiple column chi-squared (two degrees of freedom) analysis of these groups, which shows a significant difference (P = 0.007).

*Post hoc* analysis of the data with a 2x2 contingency table confirms that men who reported any same sex attraction had an odds ratio of 3.13 (95% CI: 1.47 - 6.64; P = 0.0047 by FET) for reporting a suicide attempt compared with men reporting no same sex attraction.

In another 2003 paper, (Savin-Williams *et al.*, 2003) Savin-Williams and Ream reported on two separate studies that used quite different methodologies but were interesting in that in both subjects were asked to rate their 'sexual orientation' along Kinsey's original seven point scale (from 0 = 'exclusively heterosexual' to 6 = 'exclusively homosexual'). (Kinsey *et al.*, 1948) The first was an otherwise conventional study of 51 young men (aged 14-23) attending a gay support group. All had some same sex attraction as evidenced by Kinsey self-ratings >0 and this was narrowly spread at the upper end of the scale (mean = 5.2, SD = 0.9) 20 respondents (39%) reported ever having made a suicide attempt and six (12%) reported a suicide attempt in the prior twelve months. Attempters had had their first same sex encounter at a younger age than non-attempters, and had fewer female partners, but Kinsey self-rating was not significantly associated with the likelihood of having attempted suicide.

The second was an internet-based survey of 'Queer and Questioning Youth', which elicited 1016 responses from males of which the 681 from young men (aged 13-25) in the US, Canada, UK, Ireland, Australia and New Zealand were included. 74% of these men reported 'being exclusively (34%) or predominantly (40%) homosexual'.(Savin-Williams *et al.*, 2003, p 513) They showed somewhat greater heterogeneity in their Kinsey self-ratings with a mean of 4.82 and an SD of 1.30.

In this group only 12% reported ever having tried to kill themselves and, in contrast with the support group sample, suiciders had a higher Kinsey rating, as well as reporting a lower age of first disclosure of their sexual identity to others. The concerns about internet-based sampling selecting for respondents who are socially advantaged discussed in regard to Mathy's paper (see page 182) may also apply, though probably to a lesser extent, to this study and may account for the absolute rate being at the lower extreme of the general range.

To the end of May 2005, the most recent contribution to this literature appeared to be a 2004 paper from Pinhey and Millman.(Pinhey *et al.*, 2004) They reported a school based, probability sampled study of 1381 grade 9 to 12 students on the island of Guam in the Western Pacific, including 674 males. The students were asked 'Which of the following best describes you? Are you (1) gay, (2) lesbian, (3) bisexual, (4) heterosexual, (5) not sure or (6) don't know?'.(Pinhey *et al.*, 2004, p 1204) Responses (1), (2) & (3) were recorded as a 'same sex orientation' and the remainder as otherwise. Thus the study was based on sexual identity and, in this age group, would have failed to identify same sex attracted individuals who had not yet adopted such an identity (but might still have been at increased risk of suicidal behaviour). 4% of both boys and girls were classified as having a 'same sex orientation' according to this schema.

This study did not report raw data and so the absolute rates of suicide attempt history cannot be definitively ascertained. The rate for males in the whole sample was 15% (which would be considered high in a general North American or Australian sample) however, and 'same sex orientation' boys had an odds ratio of 5.01 (95%CI: 2.13 - 11.77) of reporting an attempt compared with the remainder of the male respondents. *Post hoc* modelling of these figures suggests that the rate in the 'same sex orientation' boys must have been about 43%, and that in the remainder of the boys about 14%, to yield this result.

#### Australian Studies

Four original studies were identified that examined the prevalence of attempted suicide among homosexually active men in Australia. Burich and Loke looked at the issue 'from the opposite direction' to most studies when they interviewed 33 consecutive male attempted suicide casualty attenders for a paper published in 1988.(Buhrich *et al.*, 1988) 33 age-matched male 'non-parasuicide' casualty attendees were interviewed as controls. 13 of the 33 suicide attempters (39%) reported some homosexual interest or activity compared with 10 of the 33 controls (30%). This was not a significant difference but the sample size was small.

Nicholas and Howard published in 1998 the findings of a study that compared questionnaire responses of 57 gay-identified males aged 18-24 with those of 54 age-matched heterosexual controls.(Nicholas *et al.*, 1998) Subjects were recruited through 'personal referral, universities gay-identified support services and welfare agencies'. 16 of 57 gay males (28%) reported having attempted suicide compared with 4 of 54 heterosexuals (7%). *Post hoc* contingency table analysis of these figures identifies a significant difference between the two groups at the P = 0.006 level by FET. Gay-identified participants also perceived their attempts as significantly more serious and were more likely to have required medical attention after an attempt. Risk factors for attempted suicide among the study subjects included younger self-identification as gay, perceived violence in the household of rearing, experience of sexual assault, low levels of perceived paternal support and having experienced verbal violence from strangers.

Also published in 1998, was a study by Kelly's group of a clinical convenience sample of 229 gay and bisexually identified men of whom the majority (164, 72%) were HIV positive.(Kelly *et al.*, 1998a) No heterosexual control group was employed. The age range was 20 – 60 years with a median of 33. A comprehensive battery of psychological tests was administered and prior suicide attempts were ascertained. 29% of HIV negative and 21% of HIV positive men reported having attempted suicide, which was not a significant difference.

Predictors of having attempted suicide in the group were a history of injecting drug use, a personality style with an externalised locus of control, a family history of attempted suicide and a lifetime past history of major depression.

Most recently, Tony Jorm's group at the Australian National University reported findings from a community sample study of 2404 20-24 year olds and 2530 40-44 year olds in Canberra in 1999-2001.(Jorm *et al.*, 2002) These represented response rates of 58% of the younger people and 65% of the older group identified demographically.

Among a wide range of questions, in a comprehensive questionnaire, was an inquiry about sexual identity and a five-component instrument on suicidality. This analysis separated results for people who self identified as bisexual from those who identified as homosexual, which has been rare in the literature, and found overall that bisexually-identified people had lower levels of mental health than self-identified homosexuals, who in turn were worse off than self-identified heterosexuals. The design of the suicidality component was such that (as in Russell and Joyner's study, Russell *et al.*, 2001b) participants were asked only about the previous year and, in addition, only respondents who answered yes to a question about suicidal ideation were asked about suicide attempt. Thus 'impulsive' suicide attempts without prior ideation might not have been captured. Similarly, it can be imagined that one possible internal answer to a question about having 'thought about taking your own life' could be 'I haven't thought about it, I've tried it!'. This response might have registered as a 'no' to the question and thus the attempt would not have been captured.

Professor Jorm kindly provided raw data since only aggregated data for the suicide instrument were published and no gender breakdown regarding suicidality was undertaken in the paper. In common with other community surveys, relatively low rates of self-reported non-heterosexual identification were identified in this study. Among the men, 30 of 2332 (1.3%) self classified as homosexual, 29 (1.2%) as bisexual and a further 31 (1.3%) answered 'don't know' to the orientation question. This yields a total of 90 respondents (3.9%) identifying as GB or uncertain.

Among these men, four (4.4%) reported a suicide attempt in the prior year, compared with 18 (<1%) of the 2242 heterosexually-identified respondents. Despite the small numbers in the non-heterosexual cells, *post hoc* contingency table analysis demonstrates this to be a statistically significant difference at the P= 0.003 level (by Chi Squared with Yates Correction), with an odds ratio of 5.5 (95% CI: 1.9 - 17.3) for non-heterosexually-identified men having attempted, compared with heterosexually-identified men.

Only one of the 31 'don't know' men reported a suicide attempt, and so even if this group were considered 'heterosexual', the difference remains significant at the P= 0.008 level, with an odds ratio of 6.4 (95% CI: 1.8 - 22.1) for gay and bisexually identified men having attempted compared with the rest of the cohort.

Rates of reported suicide attempt among the women in this study were remarkably low (36/2554 = 1.4%). Even accounting for the fact that the rates relate only to the prior year, this suggests that the questionnaire was relatively insensitive for attempted suicide. There is no reason to believe *a priori* that this insensitivity would apply differentially on the basis of sexual orientation, however, and so the difference in the male rates calculated above remains of interest.

#### Summary

Since Saghir's historical detection of a suicide attempt rate of 7% among politically-active gay men immediately post-Stonewall,(Saghir *et al.*, 1970) 31 other peer-reviewed studies have been identified, which estimate the general lifetime frequency of attempted suicide among gay and bisexually-identified men between 13% and 43%.<sup>\*</sup> In all studies where heterosexual controls were studied, the rate among homosexually active men was higher than the controls and this difference was significant in all studies with large sample sizes. Estimates at the higher end of the prevalence range were generally seen in studies involving convenience samples, especially where these samples had a preponderance of people around the age of 21 years.

The studies that employed population based sampling generated rates in the range from 12% to 36% with a trend again toward the higher figures being seen in younger populations (Bagley and Tremblay's study found that only 6% reported a 'serious' attempt, (Bagley *et al.*, 1997) but an additional 16% reported other self-harm that would probably have been considered suicidal in the other studies).

Herrell's unique twin-controlled study suggested a prevalence toward the lower end of the spectrum in a group of middle aged men who had engaged in military service, (Herrell *et al.*, 1999) and D'Augelli's study of people over 60 identified the low estimate of 13% among people who had survived to this age.(D'Augelli *et al.*, 2001a) Jorm's recent Australian study did not estimate lifetime prevalence but yielded rates of recent attempted suicide among gay and bisexually identified men that, while low (probably due to an insensitive instrument), were significantly higher than those for heterosexually-identified men.(Jorm *et al.*, 2002)

Studies in the United States, New Zealand, French-speaking Switzerland, Australia and Guam yielded broadly congruent results.

<sup>&</sup>lt;sup>\*</sup> This excludes the two internet-based studies, which had rates of 8.4% and 12%. As discussed in the section on Mathy's study (see page 182) internet-based sampling may well select for social advantage that is negatively correlated with suicidality.

There now seems little doubt that homosexually active men are at substantially higher risk for attempted suicide in adolescence and throughout adult life. There appears to be a peaking of this potential around the age of 21 years but substantial rates are seen in both younger and older men up to the age of 60. Looking at the issue from the other direction, Bagley and Tremblay's general community sample suggested that more than half of suicide attempters in the 18 – 27 year old population studied would have been same sex attracted men.(Bagley *et al.*, 1997) There is some evidence that suicide attempts in same sex attracted males may be of higher potential lethality and it seems unlikely that such a marked tendency would not also be related to an increased risk of completed suicide. It has been argued above that the completed suicide data themselves are not inconsistent with this hypothesis, and indeed Jesdale and Zierler's study provides compelling support for it.(Jesdale *et al.*, 2002)

#### Suicidal ideation

A number of the studies already discussed have looked at suicidal ideation in addition to a life history of attempted suicide. Studies already mentioned will not be described in detail here and the reader is referred back to the previous section for information about sampling methods.

The 1969-70 Kinsey Institute interviews reported by Bell and Weinberg (1978) and by Harry (1983) revealed that 35% of 683 gay-identified white men reported having 'seriously considered' suicide, compared with 11% of 337 matched 'heterosexual' controls.(Harry, 1983, p 353) On *post hoc* analysis with a 2x2 table, these data yield an odds ratio of 4.24 (95%CI: 2.92 to 6.15, P < 0.0001 by FET) for gay-identified men having considered suicide compared with the controls.

In Schneider's 1989 study, 52-59% of the convenience sample of 108 gay men aged 16 to 24 reported having had 'serious suicidal thoughts' at least occasionally.(Schneider *et al.*, 1989, p 384)

Two reports on participants on the Multicenter AIDS Cohort Study (MACS) have examined suicidal ideation. Joseph published a paper in 1990 which found that among the 436 gay identified men recruited into the MACS from Chigaco, 45% reported having 'thoughts of ending my own life' on at least one six monthly review during three years of follow up.(Joseph *et al.*, 1990, p 613) Schneider also published two papers in 1991 that looked at 778 gay identified men from the MACS cohort.(Schneider *et al.*, 1991a; Schneider *et al.*, 1991b) About half of these men were HIV positive and their mean age was 36 years. 27% described some suicidal thought in the prior six months. The symptom was associated with higher depression scores, loneliness measures and, to a lesser extent, HIV-related contextual features such as having a friend with AIDS. The second paper found no difference in the prevalence of suicidal thought between HIV positive and HIV negative men though different conceptual models were offered by the two groups for understanding it.

Proctor and Groze found, in their convenience sample of 221 gay people including 159 men, that in addition to the 40% already described who had attempted suicide, and additional 26% had 'seriously thought about it' leaving only 34% of the sample who had neither seriously contemplated nor actually attempted suicide.(Proctor *et al.*, 1994, p 508) Rotheram-Borus and colleagues found, similarly, in Hispanic and black young men that in addition to the 39% who reported a suicide attempt, a further 37% had 'thought about suicide every day for a period of at least a week'.(Rotheram-Borus, 1994, p 502)

Faulkner and Cranston's study of Massachusetts high school students, reported in 1998, found that 42% of homosexually active respondents reported having 'seriously considered suicide' compared with 29% of students with only heterosexual experience (this was a significant difference at the <0.05 level).(Faulkner *et al.*, 1998, p 265) 30% of homosexually active students compared with 26% of only heterosexually active students reported having made a suicide plan but the data in this study were not broken down by gender.

In Herrell's twin study (described on page 176), the rate of suicidal ideation for homosexually-active twins was 55% compared with 25% among their exclusively heterosexual brothers, (Herrell *et al.*, 1999) while in Fergusson's New Zealand birth cohort, 68% of homosexually identified or active participants had experienced suicidal ideation compared with 28% of exclusively heterosexual men. (Fergusson *et al.*, 1999)

The Belgian study of 404 young people (including 208 males) drawn from gay holiday camps and secondary classes reported by van Heeringen and Vincke found that 38% of 'homosexual and bisexual' respondents (determined on the basis of reported sexual activity and sexual fantasy) had 'considered attempting suicide' compared with 22% of 'heterosexuals'.(van Heeringen *et al.*, 2000, p 495) The raw figures were not broken down by gender but the paper reports that there was a significant difference for both genders when considered separately with 'homosexual or bisexual' males having an odds ratio of 2.45 of having had suicidal ideation (95%CI: 1.16 - 5.17, P = 0.013).

Cochran and Mays' analysis of the NHANES III survey data showed rate of lifetime suicidal ideation of 41% among it's small group of homosexually-active men compared to 17% among men who said the were exclusively heterosexual and 13% among reportedly celibate men.(Cochran *et al.*, 2000)

Blake, in her population survey of adolescents at school, identified significant differences between homosexually attracted or active students and heterosexual respondents for having 'seriously considered suicide' (47% cf 25%) and having 'planned how to attempt suicide' (42% cf 18%).(Blake *et al.*, 2001 943)

In a large convenience sample of 912 non-heterosexually-identified Latino men, Diaz and coworkers identified that 17% had 'thought of taking their own lives' but no control group was employed for comparison;(Diaz *et al.*, 2001) while in an intriguing, recently-published clinical sample, among 68 gay and bisexuallyidentified men attending for treatment of amphetamine dependence, 19% of HIV negative men reported suicidal thought while none of the HIV positive men did.(Shoptaw *et al.*, 2002)

In Russell and Joyner's large 2001 study of US secondary students, 15.4% (95% CI: 11.9% – 19.0%) of same sex attracted males reported suicidal thoughts in the prior 12 moths compared with 9.7% (95%CI: 8.7% - 10.7%) of other males; (Russell *et al.*, 2001b) while in D'Augelli's uncontrolled study of 195 young gay and bisexually-identified males recruited from community organisations, reported in the same year, 75% reported ever having had suicidal thoughts and 55% reported such ideation in the prior 12 months.

In Remafedi's 2002 venue-based sample of 255 homosexually active men, suicidal ideation was rated over the very short time frame of the previous month and 19% reported that they had experienced such thinking within that period.(Remafedi, 2002)

Also in 2002, Rutter and Soucar published a study of young people aged 17-19 that on first inspection appears to refute an association between same sex attraction and suicidal ideation.(Rutter *et al.*, 2002) They did not report raw rates of suicidal ideation but instead used suicidality scales such as the 'Suicide Probability Scale' and the 'Suicide Questionnaire', and compared the responses of 100 people aged 17-19 (including 50 males) 'recruited from a community support agency and an urban university'.(Rutter *et al.*, 2002, p 291) They divided the 100 respondents on the basis of self-reported 'sexual orientation' into homosexual (n= 26), heterosexual (n= 50) and 'bisexual/questioning' (n = 24) and found no significant difference between the three groups on any of the measures. They then compared homosexually-identified males (n = 16) with heterosexually-identified males (n = 25), omitting the nine boys who identified as 'bisexual/questionning', and again found no difference.

This study appears to have some major methodological problems. Firstly, the sample size is very small, especially when attempts are made to draw conclusions about the males in isolation. Secondly, the paper gives little information about recruitment strategies but the finding that a full half of the sample had sexual identities other than 'heterosexual' suggests that there was a deliberate attempt to recruit people of sexual diversity. The absence of information about how this was done makes it impossible to assess the recruitment techniques as a source of bias. Thirdly, the analysis of so small a sample by division into three strata rather than two (say, heterosexuallyidentified vs others) reduced the chance of finding a significant difference if it had been present. On the Suicide Probability Scale 'Suicidal Ideation' subscale, for example, the mean scores were 12.38 for heterosexually-identified 14.31 respondents, for homosexually-identified and 14.95 for 'bisexual/questioning' young people. These differences are reported to be nonsignificant, but had the analysis been done with sexual identity as a dichotomous variable, a significant difference may have been found. No raw data were provided, precluding the possibility of *post hoc* analysis. Similarly, when males were considered alone, the 'bisexual/questioning' category was excluded for reasons that are not explained in the paper. Since it is likely that these people might have had the highest rates of suicidal orientation, this was a curious decision.

In summary, Rutter and Soucar's paper has a small sample size, fails to provide raw suicidal ideation rates and has methological problems so significant as to raise serious concerns about its validity.(Rutter *et al.*, 2002)

Mathy's internet-based study also found no significant difference in suicidal ideation on the basis of sexual identity for respondents for some of the continents on which it reports.(Mathy, 2002) Its most statistically robust findings were on men from North America, where 25.4% of homosexual and bisexually-identified males reported suicidal orientation compared with 13.8% of heterosexually-identified males, with an odds ratio of 2.1 (95%CI: 2.0 - 2.3).

Significant differences were also found among males from South America (OR: 6.9, 95%CI: 2.7 - 17.9) and Asia (OR 3.8, 95%CI: 1.6 - 9.1). For males from Australia (27.9% cf 21.5%) and Europe (15.7% cf 11.0%), while the odds ratios were greater than 1 (1.4 and 1.5 respectively), the differences were not statistically significant. The concerns raised on page 182 about the potential for bias towards less suicidal respondents in Mathy's study apply equally to her findings on suicidal ideation.

Paul and colleagues' large study of homosexually active men, recruited by a probability based telephone technique, asked about having 'ever made a plan for committing suicide', which probably reflects a more intensely suicidal mental state than having merely 'thought about suicide' or even having 'seriously thought about suicide'.(Paul *et al.*, 2002, p 1339) They found that 21.3% of homosexually active men reported ever having made such a plan. The concerns raised on page 182 about bias that might be introduced by the telephone-based sampling technique, also apply to this result.

In McBee-Strayer's small sample of gay, bisexual and lesbian-identifying people recruited through social organisations, 91% of respondents reported some suicidal thoughts, 41% 'serious consideration of suicide' and 23% had made a suicide plan.(McBee-Strayer *et al.*, 2002, p 277) These results were not broken down by gender in her 2002 report.

The New Zealand birth cohort study reported by Skegg's group in 2003 showed that among 480 26 year old males, 25% of the eight with 'persistent major same-sex attraction' and 20% of the 45 men with 'minor same sex attraction' reported 'suicidal ideation' in the prior year, compared with 8% of the 427 men with 'opposite-sex attraction only'.(Skegg *et al.*, 2003, p 543)

In Savin-Williams' 2003 paper, 71% of young men from a gay support group reported ever having considered suicide, while 54% of 681 young same sex attracted men in an internet-based survey reported such contemplation, with 20% reporting having made such a plan in the prior year.(Savin-Williams *et al.*, 2003)

In Pinhey & Millman's recent report on secondary students in Guam, identified a 1.9 odds ratio for suicidal ideation among boys but, in contrast with the figures for suicide attempt (see page 185) this difference was not statistically significant.(Pinhey *et al.*, 2004)

#### Australian Studies

Kelly and coworkers employed a 14 point scale derived from a series of questions to measure the extent of suicidal thought among their clinical convenience sample of predominantly HIV positive gay and bisexually-identified men.(Kelly et al., 1998a) They were able to show that HIV positive men had significantly higher suicidal ideation scores than the HIV negative men in the cohort but no non-gay controls were included to allow comparison for this assessment. Jorm's group used five yes/no questions to assess suicidality over the prior year but (as discussed above) suicide planning and actual attempt were only ascertained if a question about having 'thought about taking your own life' were answered affirmatively.(Jorm et al., 2002, p 424) They found mean suicidality scores that were significantly higher (at the P= 0.001 level) in gay and bisexually identified people than in those who identified as heterosexual. Unpublished data from this study provided to the author reveal that 18 of 90 males who identified as gay, bisexual or 'don't know' in the study (20%) reported having thought about suicide in the prior year compared with 232 (10%) of the 2243 heterosexually-identified men. Post hoc contingency table analysis reveals this difference to be significant at the P = 0.006 level (by Chi-squared with Yates Correction) with an odds ratio of 2.2 (95% CI: 1.3 -3.7) for gay-identified, bisexually-identified and 'don't know' men having thought about suicide compared with heterosexual men.

#### Summary

It is not surprising that greater variation is seen between studies in ratings of suicidal ideation because of the greater dependency of outcomes on the actual questions employed. This argues for the use of standardised questions in future work. The ideation data are generally supportive of the thesis developed from the attempt data that homosexually active men in Western countries are on average more suicidal of thought and intent than their heterosexual peers.

#### **Depressive disorders**

There is a considerable literature on depressive symptoms in people of sexual diversity that has used a wide range of rating scales such as the Beck Depression Inventory (BDI)(Beck et al., 1961) and the Centre for Epidemiologic Studies Depression Scale (CES-D).(Weissman et al., 1977) Comparatively few papers, however, have focussed, as the present study has, on diagnosable depressive disorders. Because of the very wide range of instruments available to measure depressive symptoms, such ratings may be useful within the context of a particular study but comparison across studies is difficult to achieve and of doubtful meaning. The introduction of the Diagnostic and Statistical Manual (DSM) by the American Psychiatric Association in 1952, and its refinement since, is an attempt to produce discrete reproducible diagnostic entities from the complex flavours of human distress.(American Psychiatric Association. Task Force on DSM-IV, 1994) Thus when a 'Major Depressive Episode' is diagnosed by DSM criteria in Patient A in Adelaide and, by a different clinician, in Patient B in Paris, the similarity of the symptoms and state of mind the two are experiencing is sufficient to warrant consideration of a diagnostic entity by which they are both affected.

More recently, standardised instruments such as the Diagnostic Interview Schedule (DIS),(Robins *et al.*, 1981) the Composite International Diagnostic Interview (CIDI),(Robins *et al.*, 1988) the Structured Clinical Interview for DSM (SCID),(Spitzer *et al.*, 1992) and the Primary Care Evaluation of Mental Disorders,(Spitzer *et al.*, 1994) (see page 291) have become available to enable reliable and reproducible diagnosis according to DSM criteria.

This review is limited to studies that have used methods involving diagnostic criteria to measure the prevalence of depressive disorders (rather than the severity of depressive symptoms) in homosexually active men, with or without comparison groups. Many of the papers mentioned have already been cited for their assessment of aspects of suicidality.

DSM-based tools identify the presence of either Major Depressive Episode (MDE) or Dysthymic Disorder (DD), or both (among other possible mood disorders) according to the criteria laid down in a particular edition of the DSM. MDE describes serious clinical depression that has been present for at least two weeks, while DD is a less intense condition of depressed mood, which, nonetheless, has been present and significantly impacted on function on the majority of days in the preceding two years.

Saghir and colleagues' ground-breaking 1970 study compared 89 self-identified 'male homosexuals', recruited from 'homophile organisations' in Chicago and San Francisco, with 35 unmarried heterosexual paid volunteers.(Saghir *et al.*, 1970, p 1079) In terms of depressive disorders, it assessed only for a lifetime history of one or more acute depressive episodes using an interview schedule that seems to have been written for the purpose by the authors. They defined a depressive episode as having been present when the person experienced:

1) a sustained change of mood of a depressive nature extending over a period of one month or longer; 2) a minimum of five of the following symptoms: insomnia, restlessness or irritability, loss of ability to concentrate and/or indecision, loss of interest, crying or feeling like crying, feelings of worthlessness, suicidal thoughts, suicidal attempts, feelings of hopelessness, fear of losing one's mind, loss of appetite, weight loss, and somatic symptoms indicative of anxiety such as palpitation, shortness or breath and anxiety attacks with dizziness and sweating; 3) a distinct change in the life of the person due to the depressive episode.(Saghir *et al.*, 1970, p 1081)

It can be seen that this definition is quite close to DSM definitions of an MDE, (American Psychiatric Association. Task Force on DSM-IV, 1994) (though an MDE needs only to have lasted two weeks) and thus could be expected to capture a similar range of states of being to the more formal DSM-based instruments used in later studies.

By this definition 26 (29%) of the 89 'homosexuals' compared with 9 (35%) of the 26 'controls' reported ever having had such an episode. This difference was not significant on *post hoc* analysis by 2x2 table. It should be recalled, however, that men who were willing to come forward as 'homosexual' subjects in 1970, particularly those who were active in 'homophile organizations', are quite likely to have been selected for comparative mental health and resilience. Nonetheless the study remains interesting for historical reasons.

No further studies using diagnostic measures appear to have been published in the succeeding eighteen years until Atkinson and colleagues assessed 56 'homosexual men' from a larger cohort 'being followed up in a longitudinal study of health outcome' in San Diego, USA.(Atkinson *et al.*, 1988, p 860) They did not report how men in the cohort were originally recruited or reference the larger study. 45 of the men were HIV positive (HIV+), including 15 who met the criteria for an AIDS diagnosis, and 11 were HIV negative (HIV-). They also recruited a 'control group' of 22 'healthy male heterosexual men (sic) through a service organisation in San Diego'.(Atkinson *et al.*, 1988, p 860)

Subjects were assessed with the DIS using DSM-III criteria. Six of the 58 'homosexual men' (10.3%), including one of the HIV- men, met the criteria for an MDE within the last six months, compared with none of the 22 'heterosexual controls'. This is not a significant difference on *post hoc* 2x2 table analysis (OR: 5.57; 95%CI: 0.301 to 103 – 0.5 added to each value to allow comparison in presence of a zero cell). In the analysis of lifetime history of an MDE, 17 (29%) of the 'homosexual men' gave such a history compared with 2 (9%) of the 'heterosexual controls'. The difference in this second analysis was not statistically significant either (OR: 4.15; 95%CI: 0.871 to 19.7) but the numbers in the study were small.

Perry and coworkers, writing from New York in 1990, assessed 134 'homosexual/bisexual men' recruited through newspaper advertisements offering free HIV testing.(Perry *et al.*, 1990, pp 89-90) Subjects were assessed before they were HIV tested, but 103 were subsequently found to be HIV- and 31 to be HIV+. The authors used the version of the SCID based on the 'III-R' edition of the DSM to diagnose a range of disorders including MDE and DD.(Spitzer *et al.*, 1992)

They found that 7 (5%) of the 134 men in their sample met the criteria for a current MDE at the time of assessment and there was no significant difference in rate between men who subsequently tested HIV+ and those who tested HIV-. 41 of the 134 men (31%) had had an MDE at some stage in their lives and again there was no significant difference in this characteristic on the basis of the HIV result.

Eight men in Perry's sample (6%) met the criteria for a current DD at the time of assessment, and this condition was not significantly related to HIV result either. Lifetime prevalence of DD was not reported in the paper. No heterosexual comparison groups were used in this study.

Also in 1990, Joseph's group reported on a cohort of 436 'gay men' without AIDS who had been enrolled in the Chicago component of the Multicenter AIDS Cohort Study (which recruited 'gay men' through a variety or organisations and venues in 1984/85) and had attended six, six-monthly trial visits.(Joseph *et al.*, 1990) HIV testing had not become widespread in the US by this time and most men in this group did not know their HIV status during the period of the assessment. Assessment for MDE using the DIS was introduced from the fourth of the six visits documented. Joseph's group reported that 182 of the 436 men (42%) had a current diagnosable MDE on at least one of the three study visits at which is it was sought over eighteen months. Neither true cross sectional rates nor lifetime rates are discernable from the report.

In 1991, Williams and coworkers reported on diagnostic interviews with 208 'homosexual men' recruited from through gay organisations and an advertisement in a gay newspaper in New York.(Williams *et al.*, 1991) 124 men were HIV+ and 84 HIV- at the time of assessment. Like Perry's group, they used the DSM-III-R version of the SCID. They found that 7 of the 208 men (3%) met the criteria for a current MDE at the time of assessment and again this rate was not significantly associated with the HIV status of respondents. The lifetime prevalence of MDE was 33% (reported by 68 of 208 respondents) and again there was no association with HIV status. Only three of the respondents in this study (1%) met the criteria for current DD, and all three were HIV+. Lifetime DD prevalence was not reported and no heterosexual comparison group was investigated.

In a rare study from outside the Anglophone world, Gala and colleagues from Milan, Italy, published in 1993 on their findings in 94 HIV positive 'gay men', among a larger group of people with HIV, who were recruited at HIV testing but assessed at least 20 months later.(Gala *et al.*, 1993) They appear to have used unstructured clinical assessment to make diagnoses according to DSM-III-R criteria. They reported that 16 of the 94 (17%) met the criteria for a current MDE and 5 (5%) for current DD.

In 1994, Perkins and coworkers reported on assessments of 169 'homosexual men' recruited 'from county health departments, from organizations supported by the homosexual community, by word of mouth, and by newspaper advertisements' in North Carolina, USA. (Perkins *et al.*, 1994, p 234) 71 were HIV- and 98 HIV+ but without symptoms of HIV disease. Perkins' group used the DSM-III-R version of the SCID and found that 2 (3%) of the HIV negative and 8 (8%) of the HIV positive subjects met the criteria for an MDE at the time of assessment, yielding a cross sectional prevalence of 10/169 = 6% in the whole group. The difference on the basis of HIV status is not significant on *post hoc* 2x2 table analysis (OR: 2.82; 95%CI: 0.580 to 13.7).

The lifetime prevalence of MDE was 60/169 = 36%, and rather curiously, a *post hoc* 2x2 table reveals a significantly *lower* rate among the HIV+ men (28/98 = 29% vs 32/71 = 45%; OR: 0.488; 95%CI: 0.257 to 0.925). None of the HIV+ men were diagnosed with current DD while two (3%) of the HIV-men were. No assessment for lifetime prevalence of DD was undertaken and no heterosexual comparison group was included in the study.

In 1995, Johnson and coauthors including Williams published a paper comparing rates of 'Axis 1' orders like MDE in 'homosexual men' with or without associated 'personality disorders',(Johnson *et al.*, 1995, p 551) but this paper appears to refer to the same cohort, and probably the same assessment, as Williams' 1991 paper considered above.(Williams *et al.*, 1991) Thus it will not be discussed further.

Rabkin and colleagues, also from New York, published in 1997 on assessments of 183 HIV+ and 84 HIV- 'gay men' recruited 'through flyers posted at HIV organizations, in Chelsea bookstores community posters (a gay neighbourhood), and word of mouth'.(Rabkin *et al.*, 1997, p 147) Close scrutiny of the paper reveals that '[a]ll seronegative subjects and 69 (37%) of the HIV+ men' had been part of Perry's 1990 study discussed above, but they appear to have been re-assessed at this later stage in the history of the HIV epidemic in New York and so the results of the study will be reported here.

For this assessment the DSM-IV version of the SCID was used. 21 of the 267 'gay men' in this study (8%) met the criteria for a current MDE at the time of assessment and no significant difference in prevalence was seen comparing HIV+ with HIV- men. 106 (40%) had ever had such an episode, and again this rate was not significantly associated with HIV status. DD was not reported in this study and no heterosexual comparison group was employed.

In 1998, a group of Australian psychiatrists with Kelly as first author reported diagnoses made with the DSM-III-R version of the DIS (among other measures) in 229 'homosexual and bisexual men recruited from three Australian centres' through 'hospital and community sites (e.g. specialist HIV outpatient clinics), AIDS/HIV support services and agencies, ... volunteer organisations ... advertising and HIV testing services'.(Kelly *et al.*, 1998b, p 443) Findings concerning suicidality in the same men were published separately and are discussed on page 187. 65 participants were HIV- and 164 were HIV+.

Because some subjects had advanced HIV, the authors used two sets of criteria for current (last six months) MDE, one of which excluded depressive symptoms thought to be attributable to coexisting medical illness (the strict DSM criterion) and one that did not. By the two measures, either 36 (16%) or 38 (17%) could be diagnosed with a current or recent MDE. For lifetime history of MDE the numbers were either 66 (29%) or 80 (35%). For none of the comparisons was there a significant difference between HIV+ and HIV- respondents.

DD was only reported in terms of lifetime prevalence and 30 (13%) met the criteria for ever having had the disorder. Again the prevalence did not vary significantly by HIV status.

Richardson and coauthors reported in 1999 on the results of assessment using the CIDI of 243 homosexually active African American men aged 18-50 from Los Angeles recruited through HIV test sites, social service agencies, churches, gay organisations and public media advertisements.(Richardson *et al.*, 1999) 76 were HIV- and 167 were HIV+. Since the study was not primarily concerned with depression prevalences they reported only the combined prevalence of current MDE or DD or both as determined by the CIDI. On this basis 28 (12%) could be diagnosed with a current disorder and there was no significant difference in prevalence between HIV+ and HIV- men.

The New Zealand birth cohort reported by Fergusson and colleagues and discussed with regard to suicidality on page 176, was also assessed using the DIS at age 15/16 and then with the CIDI at ages 18 and 21.(Fergusson *et al.*, 1999) 20 (71%) of the 28 young people who were either homosexually or bisexually identified or reported homosexual activity after age 16 were diagnosed with an MDE on at least one of the three assessments, compared with 374 (38%) of the 979 participants who reported being exclusively heterosexual (OR: 4.04; 95%CI: 1.76 to 9.28, P = 0.0006). DD was not reported in this study.

In 2000, Baldewicz and co-workers reported that the prevalence of current MDE among 159 'homosexual men' (90 HIV+, 69 HIV-) recruited for a bereavement intervention, all of whom had lost 'a close friend or intimate partner to AIDS' in 6 months before enrolment, was 16% (26/159). (Baldewicz *et al.*, 2000) A modified version of the DSM-III-R version of the SCID was used for this assessment. No association with HIV status was observed, but, interestingly, Baldewicz' group reported a strong association between the diagnosis and low levels of the B-group vitamin cobalamin in the plasma of participants.

The first probability sampled population study that compared sexual diversity with mental health outcomes was also reported in 2000, by Cochran and Mays.(Cochran *et al.*, 2000) In addition to their findings on suicidality discussed on page 177, their team also used the DSM-III-R version of the DIS to identify lifetime prevalence of one or more MDEs or of DD.

They reported a lifetime prevalence of MDE of 15% among the 78 males who reported homosexual activity compared with 6.5% among the 3214 men who reported only female sexual partners. For DD the prevalence in homosexually active men was 6.6% and for men who were only heterosexually active it was 4.7%. Neither of these differences was reported to be statistically significant but *post hoc* 2x2 table analysis of the raw rates for MDE in the two groups yields a significant odds ratio of 2.61 (95%CI: 1.39 to 4.91). The 211 men who reported no sexual activity were considered separately from the two groups reported here.

In early 2001, Sandfort and colleagues from the Netherlands reported a study based on a probability sample Dutch people selected through a random household sampling technique, of whom 5998 (including 2878 men) provided full data and were included in the analysis.(Sandfort *et al.*, 2001) Sexual behaviour was categorised in terms only of activity in the twelve months before assessment. 82 male respondents reported having been homosexually active during this period and 2796 did not. Current (twelve month) and lifetime MDE and DD (among other disorders) were assessed using the CIDI. The findings from this study are presented in Table 3.

Disorder	Prevalence in homosexually active respondents (n = 82)	Prevalence in non- homosexually active respondents (n = 2796)	Adjusted odds ratio*	95% CI
Current (twelve month) Major Depressive Episode	9.76%	3.93%	1.96	0.88 – 4.37
Lifetime Major Depression	29.3%	10.9%	2.35	1.39 – 3.97
Current (twelve month) Dysthymic Disorder	3.66%	1.32%	2.72	0.75 – 9.86
Lifetime Dysthymic Disorder	7.32%	3.51%	2.33	0.94 – 5.75
Any Current (twelve month) Mood Disorder	17.1%	5.19%	2.93	1.54 – 5.57
Any Lifetime Mood Disorder	39.0%	13.3%	3.11	1.91 – 5.05

Table 3: Rates of mood disorders among Dutch men(Sandfort *et al.*, 2001). \* = Adjusted for age, level of education, 'urbanicity' and relationship status.

It can be seen that recently homosexually active respondents in the Dutch population survey were significantly more likely to have a current mood disorder and to have ever had an MDE than people who were not homosexually active.

The largest and most recently published population-based study of depressive disorder prevalence in relation to sexual diversity was reported by Gilman and colleagues later in 2001.(Gilman et al., 2001) This group (which included Cochran and Mays whose earlier work has already been discussed) analysed the National Comorbidity Survey conducted in the United States in 1990-1992. This was a probability sampled national household survey of people aged 15 to 54 and had a response rate of 82%. It included 8098 people who were screened for psychiatric disorder using the DSM-III-R version of the CIDI. Those 'who screened positive for a lifetime disorder, plus a random subsample of other respondents' (n = 5877) underwent a more extensive interview that included questions about the gender of sexual partners in the prior five years. Gilman's analysis excluded people who reported no sexual activity in that period and its results were weighted back to the results of the US Census to account for the sampling and tiered interview process. Unlike Sandfort's group, they reported separate results for males and females. By this method, they found a 10.3% current (twelve month) prevalence of MDE among the 74 men reporting any male partners in the prior five years compared to 7.2% among the 2310 men reporting only female partners. For DD, the prevalences were 1.9% and 1.1% respectively. Neither of these differences was reported to be statistically significant. They also presented odds ratios for a lifetime prevalence of the disorders, adjusted for age, educational attainment, household income, race/ethnicity and marital status. Men with same sex partners had an adjusted OR of 1.5 of having had an MDE and 1.1 for having had DD compared with men who had only been heterosexually active, but both values had wide confidence intervals and neither was statistically significant.

It should be recognised that both Sandfort's and Gilman's study demonstrated low reported rates of homosexual activity. In Sandfort's only 2.45% of males reported any same sex activity in the prior twelve months and in Gilman's only 2.62% reported homosexual activity in the prior five years. Both of these rates are somewhat low for western population samples. Bagley and Tremblay, for example, found that 69 (9.20%) of 750 males (aged 18-27) in a suburban population sample in Calgary Canada reported sex with another male in the prior six months,(Bagley *et al.*, 1998) and Diamond, in a review of several studies concluded that about 5 - 6% of males are homosexually active.(Diamond, 1993) Gonsiorek and colleagues argue that the figure is more likely to be about 10% and suggest that a major problem facing population based studies is:

the risk involved in self disclosure, especially where studies fail to ensure complete anonymity. It is possible, indeed quite likely, that [estimates of the proportion of men who are homosexually active around 2-5%] represent an absolute minimum and that they represent homosexual individuals who are relatively open and/or who live lives within tolerant or cosmopolitan communities. (Gonsiorek *et al.*, 1995, p 43)

If Gonsiorek's group is right, and if part of the causation of depressive conditions in some same sex attracted people is being troubled about their sexual desire, it follows that population based studies would be less likely to identify same sex attraction or behaviour in the very people who are experiencing the mental health consequences of its associated stigma. As has already been argued with regard to Paul's suicidality study (see page 182), the 'gold standard' of population probability sampling may have a systematic bias that will underestimate the number of same sex attracted people experiencing emotional disorders.

#### <u>Summary</u>

From the papers reviewed it can be seen that the rate of current or recent Major Depressive Episode in homosexually active men varies considerably between studies in the range 3% to 17%. The value does seem to be somewhat dependent on the diagnostic schedule used with the SCID instruments generally yielding rather lower 'current or recent' prevalences than free-form clinical interview, the DIS or the CIDI.

The lifetime prevalence of MDE was much more consistent across the studies, with most giving a value between 29% and 39%. In all of the studies that compared homosexually active subjects with exclusive heterosexuals the rate MDE was higher in the homosexually active group and in several studies these differences were statistically significant. Being HIV positive seemed to have little impact on the likelihood of having or having had an MDE.

Fewer studies looked at the prevalence of Dysthymic Disorder. The prevalence of current DD among homosexually active men varied between 1% and 6% and the lifetime prevalence between 6% and 13%. In the few studies where heterosexual comparison was undertaken, rates in homosexually active subjects were higher but no study demonstrated a significant difference in rates.

Although the data are imperfect, the available information points to homosexually active men experiencing health inequality in regard to depressive disorder prevalence.

#### **Anxiety disorders**

Several of the studies already discussed with reference to depressive disorders or suicidality also reported on anxiety disorders. In addition, one additional report focused on anxiety disorders specifically<sup>\*</sup>. For the reasons discussed above for depression, this review is restricted to studies that have sought to derive prevalences of diagnosable anxiety disorders (according to DSM criteria) rather than simply to rate the severity of anxiety symptoms. Full details of studies already quoted will not be reiterated and the reader is referred to the previous sections for this information.

<sup>&</sup>lt;sup>\*</sup> Although the report was separate, the study also measured depressive disorders and these results were reported separately. See discussion of Sewell's paper below.

The 2000 publication included, with Sewell as lead author, appears to have used the same cohort as the Rabkin paper mentioned on page 202, which in turn used part of the cohort from the paper published by the same group with Williams as first author mentioned on page 200.(Sewell *et al.*, 2000)

The prevalence of anxiety disorders reported in each of the studies is summarised in Table 4 on page 209. It can be seen that there was great variation in the rate of anxiety disorders across the studies and it is difficult to compare meaningfully between them. In almost all studies where rates were compared between 'homosexual' and 'heterosexual' groups, however, the rate in 'homosexuals' was higher. In Sandfort's Dutch population study, 'homosexual' men had a significantly higher lifetime prevalence of Panic Disorder,(Sandfort *et al.*, 2001) and in Gilman's report of a US population study, men with male sexual partners in the prior five years were significantly more likely to have ever had Generalised Anxiety Disorder.(Gilman *et al.*, 2001) The potential for population probability sampling to fail to identify distressed homosexually active people in a systematic way, discussed on page 206 with regard to depression, applies equally to anxiety disorders. Thus the reported differences are likely to be underestimates.

Fergusson and team's birth cohort methodology would seem to be less likely to be subject to this effect because subjects may have come to know and trust the research team over the long course of the study.(Fergusson *et al.*, 1999) Their study showed a robust significant difference in the lifetime rate of General Anxiety Disorder (the only anxiety disorder on which it presented results) with homosexually active or attracted subjects almost three times as likely to have experienced the condition.

Thus, though the data are again less than ideal, the evidence that does exist supports the hypothesis that homosexually active men are subject to health inequality with regard to the rate at which they experience anxiety disorders.

	Year of publicn	Short term prevalence			Lifetime prevalence					
Study		Panic Disorder		Generalise Disor	Generalised Anxiety Disorder		Panic Disorder		d Anxiety der	Notes
		`homo- sexuals'	`hetero- sexuals'	`homo- sexuals'	'hetero- sexuals'	`homo- sexuals'	`hetero- sexuals'	`homo- sexuals'	`hetero- sexuals'	
(Saghir <i>et al.</i> , 1970)	1970	-	-	-	-	-	-	11.0%*	8.57%*	*'anxiety and phobic neurosis' by DSM-II criteria N ('homosexuals') = 89, N ('heterosexuals') = 35
(Atkinson <i>et al.</i> , 1988)	1988	-	-	23.2%	0%	5.36%	0%	39.3%	0%	Short term = six months. N ('homosexuals') = 56, N ('heterosexuals') = 22
(Perry <i>et al.</i> , 1990)	1990	-	-	6.72%#	-	-	-	11.9%#	-	#Combined prevalence of all anxiety disorders. N ('homosexuals') = 134
(Williams <i>et al.</i> , 1991)	1991	-	-	0.962%#	-	3.37%	-	-	-	#Combined prevalence of all anxiety disorders. N ('homosexuals') = 208
(Gala <i>et al.</i> , 1993)	1993	-	-	5.32%#	-	-	-	-	-	#Combined prevalence of all anxiety disorders. N ('homosexuals') = 94
(Perkins <i>et al.</i> , 1993)	1994	0%	-	0.591%	-	1.18%	-	-	-	Short term = one month. N ('homosexuals') = 169
(Rabkin <i>et al.</i> , 1997)	1997	1.87%	-	1.12%	-	7.12%	-	1.12%	-	Short term = one month. N ('homosexuals') = 267
(Kelly <i>et al.</i> , 1998b)	1998	2.18%	-	3.49%	-	3.93%	-	4.37%	-	Short term = six months. N ('homosexuals') = 229
(Fergusson <i>et al.</i> , 1999)	1999	-	-	-	-	-	-	28.6%	12.5%	Birth cohort observed prospectively. Lifetime= observed between ages 14 and 21. N ('homosexuals') = 28 N ('heterosexuals') = 979. OR GAD: 2.8, 95%CI: (1.2-6.5)
(Baldewicz <i>et al.</i> , 2000)	2000	0.629%	-	1.26%	-	-	-	-	-	Short term = current N ('homosexuals') = 159
(Sewell <i>et al.</i> , 2000)	2000	1.87%	-	1.50%	-	7.12%	-	-	-	Short term = current N ('homosexuals') = 267
(Sandfort <i>et al.</i> , 2001)	2001	3.66%	8.94%	1.22%	0.787%	7.32%	1.72%	3.66%	1.50%	Short term = 12 months. N ('homosexuals') = 82, N ('heterosexuals') = 2796 Adjusted OR for Lifetime PD: 4.21 95%CI: 1.65-10.77
(Gilman <i>et al.</i> , 2001)	2001	1.0%	1.4%	0.9%	1.9%	Adjustec (95%CI: N	i OR: 1.2 0.2 – 6.5) IS	Adjusted (95%CI: 1	OR: 2.8 0 – 8.0)	Short term = 12 months. N ('homosexuals') = 74, N ('heterosexuals') = 2310 Raw figures (and % for lifetime) not discernable due to weighting. Reported to 1 decimal place.

Table 4: Comparison of prevalence of anxiety disorders in reviewed studies

#### Report of childhood sexual abuse

There is a huge literature on childhood sexual abuse and its consequences. This review will focus on the relatively small number of studies identified where homosexually active men have been specifically recruited or where the sexual orientation, attraction or behaviour of adult respondents has been sought and data have been analysed on this basis to produce rates or odds ratios.

The prevalence of report of having experienced childhood sexual abuse (CSA) is highly dependent on the definition used for such an experience. Studies in the literature have varied widely with regard to the age below which an experience was deemed to meet the definition, whether the other party had to be older and if so how much, and whether the use of force or coercion were involved, as well as whether the person reporting felt that the incident was abusive. In this review the definition used will be described for each paper discussed.

Doll and colleagues reported in 1992 on data from 1001 adult men among consecutive attenders at STD clinics in Chicago, Denver and San Francisco in the United States, who reported sexual activity with another male in the prior five years.(Doll *et al.*, 1992) The data she presented in this paper appear to have been slightly revised for a later publication in 1994, relating to the same cohort and so the second paper, with Bartholow as lead author was used for this discussion.(Bartholow *et al.*, 1994)

In this study CSA had a very complex definition. Any sexual contact involving the use of force, a weapon or verbal threat experienced by a reporting person aged under 18 at the time of the incident was considered CSA. For reporters between aged 16 and 18 at the time, any sexual contact with a person more than ten years older was CSA, while for reporters between 12 and 15, sexual contact with a person more than six years older was CSA. For reporters 11 or under at the time of the incident, any experience involving anal penetration was CSA. Otherwise, sexual contact with a person four or more years older for reporters aged 6-11, or three or more years older for reporters who were 5 or younger at the time of the incident was considered CSA.

By this definition 343 homosexually active men (34.3%) reported that they had experienced CSA. The authors found that men who reported CSA were more likely to have HIV, to have recently engaged in unprotected anal intercourse and to be users of a range of substances including tobacco, crack-cocaine and opiates.

Carballo-Diéguez and Dolezal reported in 1995 on a study of 182 Puerto-Rican American homosexually active men recruited from 'both gay and nongay identified sources'.(Carballo-Diéguez *et al.*, 1995, p 597) They defined CSA as sexual contact before the respondent's 13<sup>th</sup> birthday with a person four or more years older, irrespective of whether it was coercive. By this definition 65 men (35.7%) reported having experienced CSA. In further questioning, 32 men (17.6%) recalled the encounter as having been abusive while 33 (18.1%) felt that they had engaged in the activity 'willingly and without feeling hurt by the experience'. The authors found that the men who described their CSA experience as abusive (but not those who didn't) were significantly more likely to report recent unprotected receptive anal intercourse.

In 1997 Lenderking and colleagues reported a study of 327 'homosexual and bisexual men' who were clients of a community health centre in Boston, USA, and had previously been part of two clinical studies on HIV testing and transmission.(Lenderking *et al.*, 1997, p 250) They adopted a definition of CSA as:

A sexual experience with a person at least 5 years older if the child was 12 and under, or 10 years older if the child is between 12 and 16 inclusive, with or without physical contact, and whether or not sex was wanted by the child.(Lenderking *et al.*, 1997, p 250)

By this definition, 116 men (35.5%) reported having experienced CSA. Lenderking's group reported that men with such a history were significantly more likely to have had more than 50 lifetime male sexual partners, to have unprotected receptive anal intercourse in the prior six months and to have ever lied in order to have sex.

Paul and coworkers reported in 2001 on data from their large study (n = 2881) of men 'who self identify as gay or bisexual or who report any sexual contact with other men since age 14'.(Paul *et al.*, 2001, p 563) Sampling methods and other details of the study have already been discussed on page 182. The authors appear to have included only coercive experiences but used 18 as the upper age limit for CSA. This study weighted its results according to demographic factors and did not report raw responses. By their definition, and after weighting, the authors concluded that the rate of report of CSA was 20.6%. They found significant associations between a CSA history and report of unprotected anal intercourse with casual partners and with partners known to have a different HIV status, as well as depressive symptoms, and report of frequent anal sex under the influence of alcohol and other drugs.

In 2001, Tomeo and colleagues from Fresno, California, USA, reported a study of 942 adults most of whom were university students. Only small numbers of respondents from this source described themselves as 'predominantly gay/lesbian' and so further recruiting was undertaken at 'homosexual pride events in central California'.(Tomeo *et al.*, 2001, p 537) Among the final sample were 329 men of whom 124 described themselves as 'predominantly a gay ... person'.(Tomeo *et al.*, 2001, p 538) Tomeo's group discuss 'molestation' in their paper, but their questionnaire did not use either this term or CSA. They defined 'molestation' as sexual contact at age less than 16 with a person at least five years older, irrespective of coercion or force.

By this definition, 61 of the 'predominantly gay' men (49.2%) compared with 50 (24.4%) of the 'predominantly heterosexual' men reported having been 'molested'. On *post hoc* analysis by 2x2 table, these figures yield an odds ratio of 3.00 (95%CI: 1.87 to 4.83) for 'predominantly gay' men reporting CSA compared with other men in the study. No other correlates were examined in the study.

The same authors who undertook the study of Puerto Rican men in 1995 reported a further study in 2002 of a sample of 307 homosexually active Latino men from a range of South and Central American backgrounds recruited from gay clubs and organisations in New York City.(Dolezal *et al.*, 2002) They used the same definition as their earlier study (see page 211) and found that 100 respondents (32.6%) gave a history of what they called 'childhood sexual experience with an older person'.(Dolezal *et al.*, 2002, p 168) As in Dolezal and Carballo-Diéguez' earlier study of the men reporting this experience, only a proportion (59 men or 19.2% of the whole sample) considered it to be 'sexual abuse'. Also in line with their previous work was the finding that only men who considered their experience to have been abusive had a significantly higher rates of unprotected anal intercourse and a significantly higher number of sexual partners than men who did not have a childhood sexual experience with an older person.

Early in 2003, O'Leary and colleagues published a study of 456 adult HIV positive men who had had sex with other men in the prior year. They recruited from 'AIDS service organizations ... mainstream gay environments ... such as pride events and gay bars, and public sex environments ... such as commercial sex venues and outdoor cruising areas'.(O'Leary *et al.*, 2003, p 19) They included only coercive episodes (having been 'pressured, forced or intimidated into doing something sexually that you did not want to do') under age 16 in the definition of CSA. By these criteria, 68 men (14.9%) reported having had a CSA experience. O'Leary's group found that HIV+ men with this history were significantly more likely to report having had unprotected anal intercourse with an HIV- partner or a partner whose HIV status was unknown to them in the prior 90 days. The history was also associated with increased suicidality and hostility on specific scales.

Later in 2003, Finlinson and coworkers reported another study of Puerto Rican men sampled from both New York City and from Puerto Rico.(Finlinson *et al.*, 2003) All participants in this study were users of illicit drugs and the entry criteria required injecting drug use or use of smoked crack-cocaine, confirmed by urine drug screen.

A 'targeted sampling plan' was used to recruit 1199 participants including 881 men, of who about a third were recruited in Puerto Rico and two thirds in New York.(Finlinson *et al.*, 2003) 38 of these men 'self-identified privately' as homosexual or bisexual.(Finlinson *et al.*, 2003, p 279) CSA was defined as and 'unwanted sexual encounter' under age thirteen. By this definition 10 of the 38 ('privately') 'homosexual' or 'bisexual' men (26.3%) compared with only 10 of the 843 other men (1.19%) reported such an experience. On *post hoc* analysis with a 2x2 table, these data yield an odds ratio of 29.8 (95%CI: 11.5 to 77.3) for sexually diverse men reporting CSA compared with the remaining men in this illicit drug-using sample.

The most recent paper to examine this issue was published in 2004 by Stanley and colleagues from British Columbia, Canada. They reported on a study of 192 'gay and bisexual men' recruited by random digit dialling in a gay neighbourhood.(Stanley *et al.*, 2004, p 382) They defined CSA as sexual contact at less than age 17 with a person at least five years older, irrespective of coercion or voluntariness. 50 men in their sample 26.0% reported this experience but only 19 (9.90%) considered the event to have been abusive. These researchers also administered a variety of psychological tests to their participants and found that some characteristics (such as self esteem) seem to have been adversely effected by any sexual experience under age 17, others (such as interpersonal problems) only seemed to be affected if the contact was perceived to have been abusive.

#### **Summary**

It can be seen that rates of reported CSA are highly dependent on the definition used, particularly with regard to the age limit employed and the issue of whether coercion is considered relevant. Rates among gay and bisexually identified and homosexually active men ranged from about 15% in a study that used a very narrow definition (coercive activity under age thirteen) to almost 50% in a study that considered all sexual activity under sixteen with a partner more than five years older to be CSA.

In the two studies located that assessed a heterosexual comparison group by the same methodology, homosexually active men were significantly more likely to report a CSA history.(Finlinson *et al.*, 2003; Tomeo *et al.*, 2001) Consideration of the very high odds ratio seen in Finlinson's study for a definition of CSA that included coercion (29.8) must recognise, however, that the investigation was conducted on a highly selected population of people who used injected drugs or smoked crack-cocaine.(Finlinson *et al.*, 2003)

It is of interest that, where the question has been asked, around half of the homosexually active men who have experienced sexual activity that might be defined as CSA do not evaluate that experience retrospectively as abusive. These men appear to be less subject to adverse consequences of the event. Thus, though homosexually active men appear to experience health inequality in regard to CSA, this may be exaggerated in some studies by the inclusion of experiences that the men themselves do not evaluate as having been abusive.

#### Substance use

There is a large literature on substance use in people of sexual diversity that has utilised a wide range of measures and methodologies. This review is been limited to studies that compared rates of use in homosexually active men and men who are not homosexually active.

The first large study of this issue appears to be that reported by Stall and Wiley in 1988.(Stall *et al.*, 1988) They conducted a survey of unmarried men aged 25-54 sampled on a probability basis from households in areas of San Francisco with large gay populations. 748 homosexually active men and 286 exclusively heterosexual men were recruited and the results were weighted to census data. The study found that homosexually active men were significantly more likely to be either abstainers from alcohol or heavy drinkers, but less likely to drink moderately, than their heterosexual peers. They were also significantly more likely to be current users of cannabis, nitrites, ecstasy, 'psychedelics', barbiturates, ethyl chloride and amphetamines, but not of cocaine or of opiates.(Stall *et al.*, 1988, p 68)

In 1989, Tori published a study that compared substance use by 'sexual orientation' in a very specific cultural group.(Tori, 1989) His subjects were '40 sexually active, young, homosexual men who were born and reared in Mexico and lived illegally in the San Francisco Bay Area' and 25 men from similar backgrounds who identified as heterosexual.(Tori, 1989, p 815) All were recruited via bars and Mexican restaurants and were aged under 30. Tori found that the homosexually-identified men were significantly more likely to be 'heavy' users of alcohol (58% vs 32%) and had higher average levels of use of cannabis, amphetamines, hallucinogens, 'inhalants' and 'sedatives' than their heterosexually-identified peers. As in Stall and Wiley's study, rates of use of cocaine and opiates were not significantly higher.

McKirnan and Peterson from Chicago, USA also published in 1989.(McKirnan et al., 1989) Their study subjects were 3400 respondents to a survey published in `large homosexual-oriented weekly newspaper', including 2652 а men.(McKirnan et al., 1989, p 547) They utilised the same question structure as US national surveys of alcohol and other drug use undertaken in 1979 and 1986 respectively, and compared their findings with these general population results. They found that rates of alcohol use were not significantly different overall between homosexually active men and men in the US generally, but the drop-off in consumption with increasing age seen in the general community was much less evident among homosexually active men. They also found that their respondents had higher lifetime rates of cannabis and (unlike the previously-described studies) cocaine use than men in the US community generally.

Skinner and Otis, who published in 1996, used the mailing lists of gay organisations in Kentucky, USA, augmented by snowball techniques and sampling at a Pride picnic to recruit 1067 self-identified lesbians and gay men (including 567 males) who completed a survey on drug use.(Skinner *et al.*, 1996)
Like McKirnan and Peterson, they used a question structure that would allow comparison with a general community survey, in this case a subsample of the National Household Survey on Drug Abuse, conducted in 1988, matched to the age and rough geographic location of the lesbian and gay survey respondents.

They did not undertake statistical comparison but their numerical findings were generally similar to those in the other studies discussed. Higher rates of alcohol use were found among older (>35) gay men, compared with older men in the general community. Rates of cannabis use were approximately a third higher among gay men (eg 37% cf 24% in men aged 26 – 34) rates of inhalant (nitrite) use were dramatically higher (37% cf 2%) but rates of cocaine use were similar (10% cf 7%).

Faulkner and Cranston's report of a 1993 survey of Massachusetts high school students (described on page 174 and published in 1998) also included substance use rates.(Faulkner *et al.*, 1998) They found that students with homosexual experience were significantly more likely to report frequent alcohol use, multiple instances of heavy alcohol use, frequent cannabis use, ever having used cocaine and ever having injected drugs than their peers who had only heterosexual experience. These data were not broken down by gender of respondent.

Garofalo and colleagues reported on a similar high school survey also conducted in Massachusetts two years later.(Garofalo *et al.*, 1998) In this survey a question on sexual orientation identity (rather than experience) was included and the authors compared rates of substance use reported by the 104 students who identified as gay, lesbian or bisexual with those of the remaining 4055 respondents. The students with gay, lesbian or bisexual identities were significantly more likely to report a wide range of substance use behaviours including: tobacco smoking before age 13 or in the prior thirty days; alcohol use ever, before age 13 or in the prior thirty days; cocaine use ever, before age 13 or in the prior thirty days; cocaine use ever, before age 13 or in the prior thirty days; cocaine use ever, before age 13 or in the prior thirty days; crack-cocaine use ever; inhalant use ever; anabolic steroid use ever and injection drug use ever.

An analogous survey in the US state of Vermont was reported by DuRant and coworkers, also in 1998. In this study, data were presented on 3825 sexually active males aged 12 to 18 (among a total of 21,297 respondents) of whom 278 (7.27%) reported at least one male sexual partner. Homosexual experience was found to be significantly associated with the likelihood of having used tobacco, cannabis or alcohol on school property but no data were presented on use elsewhere.

A study reported by Lock and Steiner in 1998 also used a high school survey of 1769 students aged 12-18 in northern California, USA in 1993 and 1994.(Lock *et al.*, 1999) In this case however a newly developed instrument called the Juvenile wellness and Health Survey was used. This tool included a combined score for 'General Risk Taking', which included substance use along with running away and reckless driving, but substance use levels were not reported separately in the paper. 106 respondents (5.99%) self-identified as gay, lesbian or bisexual. Although identification in one of these groups was significantly associated with 'worse' scores on the 'Mental Health Problems' scale and the 'Sexual Victimization and Risk' scale of the study instrument, no association with 'General Risk Taking' was evident.

The one included peer-reviewed study of substance use from Australia was published in 1999 by Smith and coworkers.(Smith *et al.*, 1999) They reported a probability sampled survey of 3387 Australian secondary school students, including 1499 males, conducted in 1997. 80 male respondents (5.34%) reported same sex attraction. Smith's group found that same sex attracted boys reported a significantly higher frequency of binge drinking, were more likely to have ever injected drugs (7.8% cf 2.0%) and were more likely to have injected in the prior year (3.9% cf 1.0%).

Woody and colleagues in a study published in 2001, reported on a comparison between 3212 HIV negative homosexually active men recruited from six US cities in anticipation of the initiation of HIV vaccine trials with an age-matched sample of 2481 single urban men from the 1995 US National Household Survey on Drug Abuse.(Woody *et al.*, 2001)

Men from the homosexually active cohort reported significantly higher rates of use of all of the drugs surveyed except alcohol (namely cannabis, cocaine, 'stimulants', nitrites, hallucinogens, 'sedatives' and 'tranquilisers') in comparison with the men from the general population survey.

Orenstein reported in 2001 on surveys of 2946 students in the single high school in 'a working-class, multi-ethnic Massachusetts community' in the United States, conducted in 1992-1994.(Orenstein, 2001) He used a complex array of five questions to assess sexual attraction and identity among the students, including inquiry about sexual thought, sexual experience, sexual identity, 'worry about being lesbian or gay' and 'worry about being treated differently because of sexual orientation'.(Orenstein, 2001, p 7) Although no statistical testing is reported in his paper, Orenstein demonstrates a gradient for most measures of drug use between the 2432 respondents who answered none of the questions affirmatively, across the 334 who said yes to one and the 90 who said yes to two, to the 90 students who answered three or more questions in the affirmative. 4% of those with no affirmative answers, reported the use of any drug in the last month, for example, compared with 7% of those with one, 12% of those with two and 32% of those with three or more. Similar patterns were seen for recent (though not lifetime) alcohol use and for both recent and lifetime use of cannabis, inhalants, cocaine, hallucinogens, amphetamines, barbiturates, 'tranquilizers' and opiates.

In 2002, Russell and colleagues reported an analysis of data from the US National Longitudinal Study of Adolescent Health.(Russell *et al.*, 2002) No raw numbers are presented in the report, but it was based on a survey 'more than 20 000' and follow up of 'more than 70%' a year later.(Russell *et al.*, 2002, p 199) Respondents who provided incomplete information ('12.5%') or were outside of the age range 13 to 18 ('5%') were excluded. Same sex attraction was assessed using question about having 'ever had a romantic attraction to a male' and 'a female'. Students who reported no 'romantic attractions' were also excluded (a further '11.4%'). 'Romantic relationships' were also enquired about. The authors distinguished between adolescents reporting attractions and relationships with both sexes and with just the same sex but no indication is given of the number or proportion of people in each group.

Among males, Russell's group reported that same sex (only) attracted males did not differ (from opposite sex only attracted males) for their use of any substance but 'both sex attracted' males smoked significantly more cigarettes, had been drunk more times, had ever drunk alone, had more problems caused by drinking, had used cannabis more times and had used drugs at all compared with opposite sex only attracted males. With regard to romantic relationships, males with same sex only relationships smoked *fewer* cigarettes but were more likely to have drunk alone, compared with males with opposite sex relationships more times and to have used drugs at all than those with only opposite sex relationships.

The results of this study are difficult to interpret because of the separation of young men experiencing any homosexual attraction or 'relationships' on the basis of whether or not heterosexual attraction or 'relationships' were also experienced. The absence of reporting of the numbers (or even proportions) in these groups compounds the difficulty. Sexual attraction and identity are still under formation during the adolescent period and there is probably little to be gained by separating out supposedly bisexual from supposedly heterosexual people during this period. People who report attraction to (or experience with) both sexes may indeed be the most troubled by their same sex attraction. Their reports and actions may be based on dissonance between their experienced feelings and their 'preferred' identity rather than any qualitative difference in their 'sexual orientation'.

If both groups of respondents with attraction and 'romantic relationships' that are not exclusively heterosexual are taken together, the general pattern seen in the other studies is confirmed.

Eisenberg and Wechsler in 2002 reported a study of people a little further down the path of sexual development in their paper on 10,301 sexually-active 'college' students including 4091 males.(Eisenberg *et al.*, 2003) This was based on a survey of a random sample of students at 119 campuses in 39 of the United States. Of the males '5%'<sup>\*</sup> were homosexually active with '3%' reporting same sex partners only and '2%' partners of both sexes. In this study males who reported homosexually activity were no more likely to smoke tobacco or use cannabis than their exclusively heterosexually active peers. They were, in fact, *less* likely to report binge drinking and for bisexually active men this difference was statistically significant (OR: 0.54, 95%CI: 0.34 – 0.85). This rather paradoxical finding may be related to the particular social environments of US 'colleges'. As the authors comment:

the finding that men with both- and same-sex partners are less likely to report binge drinking may be due in part to their exclusion from more "mainstream" social activities in which substance use is common. (Eisenberg *et al.*, 2003, p 910)

The US annual National Household Survey on Drug Abuse provided comparison data for several of the studies already described. In 1996 (only) the survey actually included questions (for respondents aged eighteen and older only) about the gender of sexual partners in the prior twelve months. An analysis of these data was published by Cochran and colleagues in 2004.(Cochran *et al.*, 2004) They compared substance use rates for the 3992 sexually active men who indicated only opposite sex partners in the prior year with those for the 98 men who reported at least one same sex partner during that period. In an analysis adjusted for demographic confounding, the authors found significantly higher lifetime rates of use of cocaine, hallucinogens, inhalants, analgesics and 'tranquilizers' among homosexually active men. They were also significantly more likely to report recent (one month) use of cocaine and of heroin and to report daily use of cannabis (12% cf 3.9%, OR: 3.5, 95%CI 1.3-9.3) and daily use of cocaine (2.2% cf 0.3%, OR: 10, 95%CI: 2.3-47).

<sup>\*</sup> These data were reported to one significant figure only and no raw numbers were available to allow *post hoc* calculations.

This study also asked about symptoms that might indicate 'dysfunctional drug use' or drug dependence. Homosexually active men were significantly more likely to report at least one symptom suggesting dysfunctional use (OR: 2.4, 95%CI: 1.0-5.6) and this was most likely to relate to cannabis. Further they were more likely give answers that indicated that they met the criteria for frank cannabis dependence (OR: 2.8, 95%CI: 1.1 - 7.1).

#### **Summary**

Almost all of the studies reviewed show a consistent pattern of increased substance use among men who are same sex attracted, homosexually active or gay or bisexually identified, compared with other men in comparison groups or studies. Many of these differences, in several studies, were statistically significant. Some papers suggest that men who experience attraction to or have had sexual experience with both men and women may have higher rates of substance use than men who are exclusively homosexually attracted and active. The studies among adolescents are difficult to interpret in this regard, however, and 'both sex' reports in this group may bear little relation to an established bisexual identity in adulthood.

Two studies failed to conform to the general pattern. In one of these drug use was combined with other measures of 'risk taking' that may have masked the effect.(Lock *et al.*, 1999) The other sampled US 'college' students and may have reflected a particular subcultural setting where high level substance use is largely social and less related to individual determinants.(Eisenberg *et al.*, 2003)

Thus there is considerable evidence in the literature that homosexually active and same sex attracted males in Western societies experience inequality with regard to the health-related behaviour of substance use.

#### Discussion

In this chapter, the history of the construct of homosexuality has been reviewed, and the issues raised by categorisation on the basis of sexual attraction, sexual identity and sexual behaviour have been explored. The literature on the extent to which a range of health conditions affect men who are other than exclusively heterosexual has also been critically surveyed.

The data on the health characteristics of homosexually active and same sex attracted men are incomplete for some conditions, and some of the studies reviewed have relied on convenience samples because of the difficulties of identifying people of sexual diversity in population surveys. Further, there is evidence to suggest that population sampling methods may have a systematic bias that under-identifies sexual diversity in people who experience (particularly emotional) ill health.

Nonetheless, the data that are available suggest a relatively consistent pattern of health inequality, with homosexually active and same sex attracted men disproportionately affected by a range of adverse health characteristics.

Studies from Australia are uncommon in the literature, and none were identified that specifically assessed the health of homosexually active men in a smaller Australian state like South Australia.

# Chapter 4: Background to the establishment of the Care and Prevention Programme<sup>\*</sup>

In the light of the general analysis of Australian health policy and practice already undertaken, this chapter will examine the specific factors that led to the establishment of the health care and health promotion programme that is the subject of the present study.

General practitioners have been central to Australia's response to HIV infection since the very beginning of the epidemic. As early as June 16<sup>th</sup> 1983, a month before the first Australian died of AIDS, a panel including GPs David Bradford, Ian Chenoweth and Peter Meese, answered questions at a public meeting of 'the Melbourne gay community' about the new disease.(Victorian AIDS Council, 1993, p 5) In South Australia, general practitioners Peter McEvoy and Dennis Rhodes led the way in the care of people with HIV infection in the 1980s, and were joined by the author in 1990.

In the period from 1990 to 1996, 148 South Australians with HIV infection died. (Davey *et al.*, 2004) Most of them were gay-identified men and most of them were in the care of the two GPs who were then involved (Dr McEvoy had by this time left general practice). One member of the Adelaide gay community has described this period as 'like living through a war' when there were 'two or three funerals a month', and it is clear that the two GPs who supported the community during this time experienced significant stress and distress. Much has been written since about health care worker 'burnout' in several jurisdictions in the early years of HIV, and there is no doubt that this phenomenon was prevalent among South Australian workers.(Bellani *et al.*, 1996; Felton, 1998; Haviland *et al.*, 1997; Lopez-Castillo *et al.*, 1999; Miller, 1996)

<sup>&</sup>lt;sup>\*</sup> Where not otherwise referenced, the history in this chapter is drawn from the author's recollections and notes taken during this period.

It was not surprising, then, that in 1996 one of the two GPs who were closely engaged with the gay community decided to leave Adelaide and took an extended break from practice. This precipitated a sense of crisis and a current of concern in the community that 'something must be done'.

The author, in close collaboration with the AIDS Council of South Australia and the newly-independent organisation People Living with HIV/AIDS SA Incorporated, lobbied Adelaide Central and Eastern Division of General Practice for the establishment of a programme to enhance the care of people with HIV and people at risk of HIV in South Australia, and to support the recruitment and retention of GPs to work in these communities. The Division assisted with the development of a project proposal that was submitted to the (then) Commonwealth Department of Health and Family Services for funding early in 1996. A long hiatus followed that was partly related to an ensuing Federal election. Finally, in the middle of 1997 approval of funding was announced.

Before the project could be implemented, however, the Commonwealth reviewed its funding formulae for divisions of general practice. It was decided that divisions that had a large number of projects underway would have their funding reduced to allow for increased activity in smaller divisions. In doing so, as a form of compensation, funds for existing projects were 'freed up' and divisions were allowed to reallocate funds according to their own priorities. This resulted in approximately half of the funds originally approved for the gay community project being re-directed by Adelaide Central and Eastern Division and a consequent dramatic scaling back from what had originally been proposed.

None the less, the Care and Prevention Project, as it was known, began operation in January 1998 and was officially opened on April 22<sup>nd</sup> of that year by Justice Hon Robin Millhouse (then of the Supreme Court of South Australia and now Chief Justice of the Republic of Kiribati). A project centre was established at 17 O'Brien Street in the South West Corner of the City of Adelaide, co-located with a general medical practice that focuses on the care of people of sexual diversity. This centre remains in operation to the present.

In 2000, the project became part of the Department of General Practice at The University of Adelaide, and was funded to continue, as the Care and Prevention *Programme*, by the (then) South Australian Department of Human Services.<sup>\*</sup>

The Programme was conceived in the context of international, Australian and state policy in place at the time, with close engagement with the communities it sought to serve, and it has undertaken a process of strategic development in the light of changes in policy and community priorities since that time.

Since 1998, the C&PP has provided health assessment, care coordination and extended clinical services for enrolled participants as well as educational, personal and professional support for GPs and other health care workers engaged in HIV care and prevention. It employs a 0.7 full-time equivalent (FTE) Programme Director (the author), a 1.0 FTE Nurse Coordinator, a 0.8 FTE Liaison, Policy and Administration Officer and provides a range of allied health care services to enrolled participants without charge.

People who are members of groups that are epidemiologically at increased risk of HIV infection are eligible to enrol in the Programme, but it has always had a particular focus on the group most affected by HIV in Australia, homosexually active men.

Although it was set up as a service delivery programme rather than a formal research project, evaluation and continuous improvement were high priorities for the Care and Prevention Programme (C&PP) team from the beginning. As a result, extensive health information was collected, with fully informed consent, from enrolled participants when they joined the Programme and periodically thereafter. With the transfer of the Programme to the University of Adelaide in 2000 it became clear that these data provided an insight into the health characteristics of a population that had been relatively little studied in the context of Primary Health Care.

<sup>&</sup>lt;sup>\*</sup> For simplicity, in the remainder of the thesis, the terms 'C&PP' and 'the Programme' will be used to refer to the whole history of the endeavour including both the Care and Prevention Project under Adelaide Central and Eastern Division of General Practice as well as its successor, the Care and Prevention Programme at the University of Adelaide.

The Programme's Management Committee (which includes two participant representatives) decided that the research component should be formalised and in 2001 an application was made to the University of Adelaide Human Research Ethics Committee. Approval was granted for the Programme to continue as a recognised research project without modification of its operations, and this has been renewed annually since.

The 542 homosexually active men who enrolled in the C&PP between 1998 and mid-2003 comprise the largest sample of this population whose health has been studied in detail, and followed over time, ever in Australia. The data from the C&PP are also of interest because, on the basis of the search undertaken, there appears to have been no previous cohort study reported in the literature, from anywhere in the world, that followed both HIV infected and HIV uninfected homosexually active men recruited through and engaged with a Primary Health Care Service.

The author conceived the Programme in consultation with members of the communities it serves, and has managed it since it began. He devised its protocols, questionnaires and database and has undertaken all of the data analysis. The data collection was undertaken by other team members, principally Mr Michael Curry, RN.

Part 2 of this thesis, which follows, will describe the baseline health characteristics of the C&PP cohort. It will draw comparisons with data that are available on other populations of homosexually active men, and on males in the general community, to identify any health inequality between groups. Part 3 will then investigate the historical correlates that may provide insight into the determinants of these health characteristics, as well as the behavioural correlates of participants' health status, with particular regard to HIV risk-taking.

Part 4 will then consider the changes in health characteristics that have been observed in the cohort in association with participation in C&PP and Part 5 will discuss the significance of the findings and make recommendations for further investigation.

## PART TWO Characteristics of health: Were homosexually active men enrolling in a **Primary Health** Care programme subject to health inequality?

### Chapter 5: The Care and Prevention Programme cohort

#### Introduction

Part One of the thesis has surveyed the context of the present study, up to and including the background to the establishment of the C&PP and the significance of the data it may provide, in light of existing knowledge about the health of homosexually active men.

Part Two will now explore the health characteristics of homosexually active South Australian men who have enrolled in the Programme to determine the nature and extent of any health inequality (as defined on page 29) they may experience.

As a first step, this chapter will consider the recruitment and assessment processes undertaken when participants enrolled, as well as the general characteristics of the resulting cohort of homosexually active men.

#### Recruitment

Participants were eligible to enrol in the C&PP if they belonged to one or more of the following groups:

- 1. gay, bisexual or other homosexually active man
- 2. male sexually attracted to other men
- 3. HIV positive
- 4. have, or have ever had, hepatitis B or C
- 5. have ever had a sexually-transmitted disease
- 6. have ever injected drugs
- 7. sex worker

but the Programme has a stated focus on HIV positive and HIV negative homosexually active men.

All participants required referral to the C&PP by a general practitioner and so most were recruited when they attended for routine general practice care. When the Programme began there was some publicity in the local gay press, which led to a small number of people approaching the Programme team directly seeking to participate. They were provided with referral forms and asked to take them to their general practitioners for referral.

It was initially intended that enrolment into the Programme would be drawn from many general practices and advertising to GPs was undertaken through the general practice divisions across the South Australia. The Programme is colocated, however, with the only general practice that at the time had a focus on HIV and health in sexual diversity, and it has turned out that almost all participants were recruited from this source.

GPs in this practice attempted to recruit all of their patients who met the criteria for participation in the Programme. Recruitment was not directed to people who were thought to be in particular need of extended and coordinated services but was encouraged among all eligible people attending for general practice care. Formal participation rates were not collected but the GPs involved believe that only a very small proportion of people invited to participate declined.

Clearly some of the participants will have been recruited when they were attending their GP because they were unwell. Thus the sample is definitely of a 'clinical' rather than a 'population' nature. Since 85% of Australian males attend a GP during any given year however,(Royal Australian College of General Practitioners, 2001b) and recruitment was undertaken over a six-year period, it seems likely that the majority of the population of eligible people who are engaged with the practice will have been 'captured'. The participants may thus represent a 'general practice population' sample of people in the eligible groups.

This recruitment strategy will have excluded from its sample the minority of Australians who do not see GPs regularly. Jordan, Ong and Croft found, in Britain, that not seeing a GP in a particular two-year period was associated (though weakly) with higher self-reported levels of health, as measured by the Short Form 36 instrument (see page 234) at the beginning of the period.(Jordan *et al.*, 2003) Thus participants in the C&PP might be expected either to perceive themselves as somewhat less healthy, or to be somewhat more health-focused, or both, than the total population from which they are drawn, and this must be borne in mind in consideration of the data.

Moreover, the homosexually active men in the sample were recruited from those who have sought out (or stumbled upon) a general practice that is openly interested in their health and could be expected to be sympathetic to them. Such men might, similarly, be supposed either to consider themselves to be in greater need of 'gay-sensitive' care than other homosexually active people, or to be better equipped to seek out such care, or both.

#### Enrolment assessment:

At enrolment, participants underwent an extensive health assessment conducted by the Nurse Coordinator, a Registered Nurse who openly identifies as a gay male. This involved a series of computerised questionnaires in addition to collation of medical history and standardised physical examination.

All data were recorded in coded form in a database designed and written for the purpose by the author, utilising the Microsoft *Access* programme.(Microsoft Corporation, 1992-1999) The database was written on the *Access 97* version of the programme but it was converted to *Access 2000* (version 9.0.2720) when this became available. Analyses were conducted using the later version of the programme.

Prior to the commencement of the assessment, informed consent was obtained and recorded. The participant then completed the one-page paper-and-pencil screening questionnaire of the Prime-MD (see below) before undertaking a computerised health assessment.

The computerised questionnaires were usually self-completed but the enrolling nurse would assist with completion for participants who were technologically challenged. All participants were offered the option of completing each questionnaire in private if they preferred. Some questions required free text answers and many offered a 'drop down box' of answers from which the participant could choose with the result being recorded in the database as a numeric code.

All participants enrolling underwent assessment, and all of those who joined between the commencement of enrolment on March 18<sup>th</sup>, 1998, and June 30<sup>th</sup>, 2003, inclusive, provided data that were available for the present analysis.

The enrolment protocol included the following assessments for all participants:

- A demographic questionnaire designed specifically for the C&PP (see Appendix 1 on page 473 for details)
- A health baselines form to capture general and behavioural aspects of health history and status, including use of drugs (including alcohol and tobacco), designed specifically for the C&PP (see Appendix 2 on page 477 for details)
- The Short Form 36 (sf36) general health questionnaire(Ware, 1993)
- The Primary Care Evaluation of Mental Disorders (Prime-MD) diagnostic questionnaire(Linzer *et al.*, 1996)
- A sexual behaviour questionnaire based on that developed for the first Sydney Gay Community Periodic Survey(Van de Ven *et al.*, 1997)
- The Zung Depression Rating Scale(Zung, 1965)

The sf36 is a 36-item questionnaire that measures self-assessed health, function and quality of life across eight domains (see page 309 for details). The instrument has been extensively assessed for validity and reliability. Its technical manual reports no less than thirteen reliability studies, including internal consistency, test-retest and alternate-form methodologies, yielding median reliability coefficients of better than 0.80 for all scales except the two-item Social Functioning scale where the median was 0.76.(Ware, 1993) The manual also cites a wide range of validation studies including factor analyses, comparisons with others scales, population norm comparisons with patient groups.

General opinion on the instrument was well summarised by Garratt and colleagues who, in 1993, assessed the sf36 for general use in the British National Health Service. They concluded that the sf36:

satisfied rigorous psychometric criteria for validity and internal consistency. Clinical validity was shown by the distinctive profiles generated for each condition, each of which differed from that in the general population in a predictable manner. Furthermore, SF36 scores ... were closely related to general practitioners' perceptions of severity.(Garratt *et al.*, 1993 1440)

These characteristics would seem to underline its appropriateness for the present study.

The Prime-MD (see page 291) was first developed as an interview-based diagnostic tool. Both the original and a self completed version have been evaluated in large studies.(Linzer *et al.*, 1996; Spitzer *et al.*, 1999; Spitzer *et al.*, 1994) Each assessed validity by comparison with traditional diagnostic assessments by health care professionals and found good levels of sensitivity and specificity. None of the studies reported formal psychometric reliability statistics but Spitzer's 1999 paper described very similar rates of diagnosis between the self completed and interview versions of the instrument, which at least points to reliability of the question structure.(Spitzer *et al.*, 1999)

The Sydney Gay Community Periodic Survey questionnaire does not appear to have been directly assessed for reliability and validity but its authors state that it contains 'types of questions and instruments' that have 'been validated by way of triangulation in previous studies of gay men'. (Van de Ven *et al.*, 1997 763) The questionnaire appears to have been developed from an original instrument constructed for the earlier Social Aspects of the Prevention of AIDS study by Kippax and colleagues.(Kippax *et al.*, 1993) Kippax' group reported the involved collaborative process by which their questionnaire was developed, with extensive piloting and commentary from gay community organisations, and conclude that 'the production of the questionnaire ... rested on a dialogue between gay men active in the HIV/AIDS field and the survey researchers'.(Kippax *et al.*, 1993 23) This developmental process argues for the validity of the instrument.

The Zung Depression Rating Scale comprises 20 items, each answered on a four point scale, which measure the frequency and intensity of depressive cognitions and symptoms.(Zung, 1965) It has been in use for forty years and has been evaluated in a very large number of settings. It was chosen because it was in widespread use in Primary Health Care settings in Australia at the time that the Programme began. The literature on its reliability and validity was recently reviewed by Thurber and colleagues who also compared it with the depression scale of the Minnesota Multiphasic Personality Inventory in a group of 259 people presenting for vocational rehabilitation.(Thurber *et al.*, 2002) They reported that the Scale had demonstrated good Cronbach's alpha measures for internal reliability in the range of 0.79 to 0.88 in different populations, and convergent validity in comparison with a range of other depression scales. In their own sample they found that the Zung score showed good correlation with the comparator (0.77) but was superior to it in identifying people with a DSM-IV clinical diagnosis of a depressive disorder.

The remaining enrolment questionnaires were developed by the C&PP team as evaluation tools when the Programme was seen wholly as a service delivery endeavour rather than an explicit research activity. As such, they were not formally assessed for reliability and validity before their introduction and to undertake such appraisal *post hoc* would not be methodologically sound. What can be said is that in their practical application over more than five years, no evidence of reliability problems emerged. Very few participants reported difficulty with interpretation of the questions and the Nurse Coordinator reports that participants who chose to complete the questionnaires with his assistance appeared from their comments generally to have had a clear and common understanding of their meaning.(personal communication, 2005) Further, the aggregated findings from the questionnaires have been included in a series of reports on the Programme that have been distributed to participants. Informal discussion of these findings with participants, and consideration of them at community fora and planning meetings, have indicated that there was little surprise at what was found. Participants reported the results were broadly consistent with what they had believed about the health status of members of their community. This can be considered to be a form of data triangulation and suggests reasonable validity for the questionnaires.

#### Participants

Enrolment in the Care and Prevention Programme began in February 1998 and to June 30<sup>th</sup>, 2003, 604 people had enrolled. 203 (34%) reported their HIV status as positive on enrolment, 371 (61%) as HIV negative, and 30 (5%) reported having not been tested. Their self-reported genders and the sexual orientation identities of the males are shown in Figure 2.



All of the men who chose 'something else' reported having been homosexually active at some stage, making a total of 542 homosexually active or same-sex attracted men.<sup>\*</sup> It is acknowledged that this includes a small number of men (seven, in fact) who were gay, homosexually or bisexually-identified but who did not report recent sex with males. They may be regarded as 'potentially' rather than 'actually' homosexually active at enrolment, and the term 'homosexually active men' will, from here on, be taken to include them. The 'C&PP cohort' considered in the remainder of this analysis comprises these 542 men.

#### **Comparator studies**

The assessment of health inequality (as defined on page 29) between homosexually active male C&PP participants and other men requires the comparison of health characteristics of the cohort with those of other samples of men. Suitable comparison groups would include general population samples of Australians, samples of men who specifically identify as heterosexual (whom we might chose to assume would be relatively unlikely to have been homosexually active) or samples of men recruited in primary care settings (like the cohort) but not selected for sexual identity or behaviour.

The median date of recruitment for the cohort was in mid 1999.

No single sample is available that would enable comparison on the entire range of health characteristics measured in the C&PP cohort. Consequently a range of Australian population studies has been identified that were roughly contemporaneous with the C&PP enrolment and with which comparison can be made with regard to particular characteristics. These are:

the 2001 Australian Census.(Australian Bureau of Statistics, 2002a)
 Results for South Australian adult males were used in the comparisons.

 $<sup>^{\</sup>ast}$  None of the men who described themselves as 'heterosexual' reported any homosexual activity.

- the 2001 National Health Survey (NHS01), (Australian Bureau of Statistics, 2002d). This was a study of 26,863 persons surveyed in a random sample of 17,918 dwellings across Australia, weighted to the 2001 census. Results for South Australian adult males were used in the comparisons.
- the 1998 National Drug Strategy Household Survey(NDSHS98).(Higgins *et al.*, 2000) This was study of 'more than 10,000' Australians recruited through a 'geographic random sample of households'.(Higgins *et al.*, 2000 68) Results for South Australian adult males were used in the comparisons.(Fitzsimmons *et al.*, 2000)
- the 1997 National Survey of Mental Health and Wellbeing (NSMHW97).
  (McLennan, 1999) This was a survey of 'a representative sample of persons living in private dwellings in all States and Territories of Australia' with a response rate of 78% comprising '10,600 people aged 18 years or over'. (McLennan, 1999 4) Results for South Australian males were used in the comparisons. (Australian Bureau of Statistics, 1998)
- the 2001/2 Australian Study of Health and Relationships (ASHR) (Smith *et al.*, 2003) This study conducted telephone interviews with 19,307 Australians aged 16 to 59, sampled by a modified random digit dialling technique, including 10,173 men and 501 South Australian men. Responses for Australian males were used in comparisons.

All of these studies<sup>\*</sup> used probability methodologies with the goal of obtaining a representative sample of the Australian population generally. This approach differs from the recruitment of the C&PP in an important respect. As discussed on page 232, since C&PP participants were recruited during general practice attendances they represent a clinical sample (albeit a general practice one).

 $<sup>^{\</sup>ast}$  Except, of course, the census, which aims at complete ascertainment of the entire population.

Thus it might be expected that some of their health characteristics would show lower levels of health than other members of the community from which they were drawn.

In an attempt to assess for this bias, where data were available in the public domain, comparison has also been made with the men who took part in 44,308 Australian general practice encounters in 1999/2000 as part of the Bettering the Evaluation and Care of Health (BEACH) study, (Bayram *et al.*, 2003) and the 227 male respondents in the 2000 study of general practice attenders in the Whitehorse Division of General Practice in outer eastern suburbs of Melbourne. (Griffith *et al.*, 2001) These datasets may provide more meaningful comparators through which to identify health inequality between men in the cohort and Australian men generally, since C&PP participants were recruited during general practice encounters.

In addition, as an indicator of the generalisability of the enrolment findings to other populations of homosexually active men, the cohort has also been compared for relevant characteristics with respondents to the *1999 Adelaide Gay Community Periodic Survey* ('the Periodic'),(Van de Ven *et al.*, 2000) and, for HIV positive men only, with *HIV Futures II: The Health and Wellbeing of people with HIV/AIDS in Australia* ('Futures II'),(Grierson *et al.*, 2000) which also gathered data in 1999.

The Periodic is a survey of convenience samples of homosexually active South Australian men undertaken every few years under the direction of the National Centre for HIV Social Research at the University of New South Wales. The 1999 survey sampled 463 men who reported being homosexually active in the prior five years. 222 were recruited at 'four gay community venues (two social venues and two sex-on-premises venues)' and the remaining 241 were approached at the 1999 Picnic in the Park social event.(Van de Ven *et al.*, 2000 7)

Futures II was the second of four (so far) national surveys of people living with HIV conducted by the Australian Research Centre in Sex, Health and Society at La Trobe University. It was a pencil and paper mail back survey distributed to people with HIV through community groups, clinics, advertisements and through a website. 924 people returned responses including 828 men. 56 respondents (6%) lived in South Australia.(Grierson *et al.*, 2000)

#### Analytical methods

The baseline data from the cohort were extracted from tables in the C&PP database using queries. Descriptive statistics and primary comparison of HIV positive men with men who were not known to be HIV positive (see page 244) were undertaken using the GraphPad InStat computer programme.(GraphPad Software, 1998)

For interval data (such as age) comparison of means was performed using ttests with Welch's Correction unless the data were not normally distributed, when medians were compared utilising the Mann-Whitney test. For ordinal data (such as income group), medians were compared with the Mann-Whitney test. For binary nominal data (such as the proportion of men reporting having engaged in a particular discrete behaviour) analysis was undertaken using 2x2 tables to yield odds ratios, assessed for significance by Fisher's Exact Test. Means and odds ratios were determined to three significant figures. P values were determined to three significant figures up to InStat's maximum of four decimal places.

Results for the cohort were then compared with data from the comparator studies cited above (from page 238). If no significant difference with regard to a health characteristic was found between the two groups in the cohort on primary analysis, the result for the whole cohort was evaluated against the comparator study. Where there was a significant difference between the cohort groups, HIV positive men and men not known to be HIV positive were compared separately with the other studies.

Where sufficient information was provided in the comparator study reports, formal univariate statistical comparison was performed by the methods described above utilising the InStat programme.(GraphPad Software, 1998) Where cell sizes were too large for Fisher's Test in 2x2 comparisons, Chi squared analysis was employed.

Where insufficient data were available from comparator reports for statistical analysis, simple numeric comparison only was undertaken and this should be borne in mind when the meaning of any differences is considered.

## Chapter 6: Health characteristics of the cohort and comparators

This chapter will describe the health and health-related characteristics of the 542 homosexually active male participants, on enrolment into the Care and Prevention Programme cohort. In addition, where appropriate, it will compare the cohort, with regard to these characteristics, with the other samples already discussed (see page 238).

For the reasons discussed in detail on page 361, the reported sexual behaviour of participants will be included as a 'health-related characteristic' in this description and the subsequent analysis.

#### Age

The mean age of participants on enrolment into the cohort was 41.0 years, and the median 40. HIV positive (HIV+) men were significantly younger at enrolment (mean 39.2 years) than HIV negative/untested (HIV-/?) men (mean 41.9 years; P = 0.0022, t-test with Welch's Correction).



These values are very similar to the Futures II sample of people living with HIV (mean 42.1, median 41)(Grierson *et al.*, 2000) but participants were substantially older than the homosexually active men in the Periodic (median age 34).(Van de Ven *et al.*, 2000) The mean age of SA males in the 2001 census was 36.7 years.(Australian Bureau of Statistics, 2002a) Males in the BEACH study were somewhat older then those in the C&PP cohort, with a wider age range (18% aged <15, cf 0% in C&PP, 13% aged 65-74, cf 2% in C&PP and 11% aged 75+, cf 0.2% in C&PP).(Bayram *et al.*, 2003 16) Males in the Whitehorse Division Survey (WHDS) were also older than C&PP participants with a mean age of 49.7 years.(Griffith *et al.*, 2001)

#### HIV status

184 men in the cohort (34%) reported being HIV positive (HIV+) on enrolment, 333 (61%) HIV negative (HIV-), and 25 (5%) said they had either not been tested or did not know their HIV status (HIV?).

As would be expected in a sample derived from attendance at a health service, a significantly higher proportion of participants were HIV+ in the cohort than in the Periodic sample (7%; OR= 6.39; 95%CI: 4.32 to 9.46; P<0.0001 by FET).(Van de Ven *et al.*, 2000)

Among the 9589 men who provided HIV testing data in the ASHR, 40.7% had ever taken an HIV test and 0.13% were known to be seropositive.(Grulich *et al.*, 2003a) *Post hoc* analysis yields an odds ratio of 410 (95%CI: 226 to 742, P < 0.0001 by Chi squared) for men in the cohort being known to be HIV positive compared with unselected men in the ASHR. The C&PP's focus on HIV care as well as HIV prevention would of course bias strongly toward selection of people with HIV and so the high rate of HIV infection in the cohort would be expected. There is no doubt at all, however, that substantial health inequality with regard to HIV infection is present when homosexually active or gay-identified men generally are compared with other men in the Australian community.

In the ASHR, for example, the rates of known HIV infection were '0.1% among heterosexually identified men, 3.0% among homosexually identified men, and 2.7% among bisexually identified men (p< 0.001)' suggesting an approximately thirty-fold difference in prevalence.(Grulich *et al.*, 2003a 239) In South Australia, of the 799 males notified with HIV infection between 1985 and 2003, 645 (81%) reported having been homosexually active. Since, according to the ASHR only 6% of Australian males report any homosexual experience, it is clear that extreme health inequality exists with regard to this infection among South Australian men.

#### Ethnicity

41 men (8%) answered a question about identification with an ethnic group other than Anglo-Australian affirmatively. 8 people (1.5%) identified Australian Aboriginal ethnicity, 6 (1.1%) German, 6 (1.1%) Greek, 4 (0.7%) Italian, 2 (0.4%) Indian, 2 (0.4%) Maltese and twelve other individuals identified with other ethnicities of which each was the only member in the cohort. Some men identified with more than one ethnicity. 6 of the 34 men who identified non-Aboriginal Culturally and Linguistically Diverse ethnicity were HIV+ (18%).

Members of the cohort were significantly less likely to identify with an ethnicity other than Anglo-Australian than men in the Periodic, of whom 18% described such identification (OR= 0.372; 95%CI: 0.248 to 0.559; P < 0.0001 by FET).(Van de Ven *et al.*, 2000) While no direct comparison statistic is available for the general community, it is worth noting that 8.4 % of South Australian males speak a language other than English at home.(Australian Bureau of Statistics, 2002a) In the Futures II sample <2% of respondents spoke a language other than English at home.(Grierson *et al.*, 2000) In the BEACH study, 8% of encounters were with males who were reported to be from a `non-English-speaking background'.(Bayram *et al.*, 2003 16)

#### Country of birth

447 men (82%) were born in Australia. This was not significantly different between HIV+ (79%) and HIV negative or untested (HIV-/?) participants (84%). Cohort members were significantly more likely to have been born in Australia than South Australian males generally for whom the proportion was 75% (OR= 1.58; 95%CI: 1.27 to 1.97; P < 0.0001 by Chi squared). This characteristic was not recorded in the Periodic,(Van de Ven *et al.*, 2000) but 77% of respondents in Futures II reported being born in Australia.(Grierson *et al.*, 2000) In the Whitehorse Division survey, 78% of males reported being born in Australia.(Griffith *et al.*, 2001)

Of Programme participants born overseas, 49 (9% of the cohort) were born in the United Kingdom or Ireland, 17 (3%) elsewhere in Europe, 11 (2%) in Asia and 18 (3%) elsewhere in the world.



#### Geographical distribution

500 participants (92%) lived in the Adelaide metropolitan area while 42 (8%) had postcodes elsewhere in South Australia.

The City of Adelaide (postcode 5000), where the Programme centre is located had, not surprisingly, the highest number of participants resident in it (63, 12%), followed by 5031 (Mile End / Thebarton / Torrensville) with 32 participants (6%), 5082 (Prospect / Ovingham / Fitzroy) with 21 (4%) and 5006 (North Adelaide) with 19 (4%).

Other localities with more than ten resident participants were:

- 5035 (Keswick / Ashford / Black Forest),
- 5069 (Hackney / Maylands / St Peters),
- 5061 (Unley / Malvern / HydePark),
- 5081 (Walkerville / Collinswood / Gilberton),
- 5067 (Norwood / Kent Town / Beulah Park),
- 5043 (Marion / Mitchell Park / Morphettville),
- 5034 (Goodwood / Clarence Park / King's Park),
- 5063 (Parkside / Eastwood / Frewville), and
- 5008 (Croydon / Devon Park / Dudley Park).

There was some variation on the basis of HIV status, with HIV+ men slightly less likely to live in postcodes 5082 (Prospect / Ovingham / Fitzroy) and 5006 (North Adelaide) and more likely to live in postcodes 5031 (Mile End / Thebarton / Torrensville) and 5035 (Keswick / Ashford / Black Forest) than their HIV-/? counterparts. This may reflect their generally lower incomes as well as the distribution of SA Housing Trust accommodation, for which HIV+ men would be more likely to qualify.

The cohort contained a slightly but significantly greater proportion of nonmetropolitan-dwelling participants than the Periodic (8% vs 4%, OR: 1.94, 95%CI: 1.10 to 3.42, P = 0.022 by FET).<sup>\*</sup>(Van de Ven *et al.*, 2000)

It is of interest that while only a relatively small proportion of participants *currently* resided outside of the metropolitan area, almost a third (145) of the 446 Australian-born men reported having grown up in a non-metropolitan area.





<sup>&</sup>lt;sup>\*</sup> Please note also that the Periodic included 29 respondents (6%) who dwelt outside South Australia. All C&PP participants, in contrast, had South Australian postcodes.

#### Accommodation arrangements

208 men (38%) lived alone at the time of enrolment and 193 (36%) lived with a male sexual partner (of whom 8 also had other gay friends in the household). 56 (10%) lived with gay friends who did not include a sexual partner, 37 (7%) lived with parents or other relatives, 14 (3%) with a female sexual partner, 16 (3%) with heterosexual friends and 18 (3%) in other circumstances. Accommodation patterns did not vary significantly on the basis of the HIV status of participants.

Men in the cohort were very much more likely to live alone than SA males of a similar age in the 2001 census, of whom just 14% live in one-person households (OR=3.78; 95%CI: 3.18 to 4.50; P < 0.0001 by Chi squared). This characteristic was not reported in the Periodic,(Van de Ven *et al.*, 2000) but in the Futures II study, 41% of respondents reported living alone and 35% with a partner or spouse.(Grierson *et al.*, 2000)





#### **Employment status**

For the purpose of this analysis, respondents who described themselves as either employed or self-employed, full-time or part-time were considered to be employed. Overall, 287 (53% of the cohort) were employed by this definition.

HIV+ men were significantly less likely to be employed at enrolment (36% cf 65%; OR=0.413; 95%CI: 0.287 to 0.595; P<0.0001 by FET). Both HIV+ and HIV-/? participants had significantly lower rates of employment than men in the Periodic (70%; P<0.0001 for HIV+ and P = 0.0036 for HIV-/? by FET). Both rates in the cohort were also very significantly lower than that for SA males generally in the same age group, which is 81% (P<0.0001 for difference from either rate, see Figures on page 251). In the WHDS, 63% of male respondents were employed.(Griffith *et al.*, 2001) Men in the C&PP cohort generally were significantly less likely to be employed than men in the WHDS (OR: 0.699, 95%CI: 0.510 to 0.960, P = 0.032 by FET), as were HIV + cohort members (OR: 0.391, 95%CI: 0.262 to 0.582, P<0.0001). The employment rate for HIV -/? participants, however was not significantly different from that among WHDS males.(Griffith *et al.*, 2001)







#### **Occupation**

The frequency of occupation types among people who were working in the whole cohort, HIV+ and HIV -/? participants, Periodic respondents,(Van de Ven *et al.*, 2000) SA males of a comparable age,(Australian Bureau of Statistics, 2002a) and working respondents in the WHDS,(Griffith *et al.*, 2001) are listed in Table 5. Futures II did not report occupation.(Grierson *et al.*, 2000)

Occupation Type	Cohort overall	HIV +	HIV -/?	Periodic Survey (Van de Ven <i>et al.,</i> 2000)	SA Males (Australian Bureau of Statistics, 2002a)	White- horse Division Survey (Griffith <i>et al.</i> , 2001)
Managerial	22%	21%	23%	} 31%	14%	}42%
Professional	36%	31%	38%		15%	
Paraprofessional	7%	4%	7%	12%	13%	
Clerical	8%	7%	8%	} 46%		}29%
Sales and Personal Service	17%	23%	15%		}12%	
Trade	6%	8%	5%	2%	20%	
Plant & Machine Operation and Driving	<1%	1%	0%	} 10%	14%	}25%
Labouring and Related Work	4%	4%	4%	,	10%	

Table 5: Comparison of frequency of occupation types

There was no significant difference between the occupation distributions for HIV+ and HIV-/? men who were working, though the sample size for HIV+ men who were working was relatively small (n=71).

Working men in the cohort had a significantly different distribution of occupations from SA males in general, however. For example, participants who worked were much more likely to have had a managerial or professional occupation than working males in the general community (58% vs 29%; OR = 3.42; 95%CI: 2.71 to 4.33; P < 0.0001 by Chi squared) and much less likely to engage in trade, mechanical or labouring work (10% vs 44%; OR = 0.141; 95% CI: 0.960 to 0.207; P < 0.0001 by Chi squared).(Australian Bureau of Statistics, 2002a)
Workers in the cohort also had a significantly different occupation profile from those in the Periodic. Working cohort members were significantly more likely to have managerial or professional jobs (58% vs 31%; OR = 3.17; 95%CI: 2.27 to 4.41, P < 0.0001 by FET), and significantly less likely to have clerical or sales occupations (25% vs 46%; OR = 0.384; 95%CI: 0.272 to 0.542; p < 0.0001 by FET). There was no significant difference in the proportion of respondents reporting trade, mechanical or labouring work, however, (10% among working men in the cohort and 12% in the Periodic).

### Income

The median income band for the cohort on enrolment was \$15,001 - 18,000. HIV+ men had significantly lower incomes than HIV-/? (median \$9,001 to \$15,000 for HIV+ vs \$22,001 to \$26,000 for HIV-/?; P<0.0001 by Mann-Whitney Test [MWT]).

It is interesting to note also that, with regard to this cohort, the so-called 'pink dollar' cliché,(Croome, 1996) that gay men have high incomes, is a myth. The incomes of HIV+ men at enrolment were approximately half that of men of comparable age in the general community and even HIV-/? participants had a median income that was significantly lower than that of South Australian men of comparable age generally (\$26,000 - \$31,148; P<0.0001 by one sample Willcoxon Signed Ranks Test [WSRT]).(Australian Bureau of Statistics, 2002a)

The median income range for men in the 2000 WHDS was \$30,000 - \$59,999, which is much higher than even that for HIV-/? men in the cohort, despite a similar proportion in this group being employed or self employed.(Griffith *et al.*, 2001)

Income was not recorded in the Periodic.(Van de Ven *et al.*, 2000) In Futures II, income was measured over a weekly time frame and the median weekly income for (HIV+) men was `\$373.75'.(Grierson *et al.*, 2000 98) This translates to a mean annual income of \$19,435, which appears to be somewhat higher than that of HIV+ men in the C&PP cohort.



Figure 12: Comparison of income distributions

# Educational attainment

The median level of educational achievement for men in the cohort overall was Year 12.

HIV+ participants had a significantly lower median than HIV-/?. For HIV+ men the median level of achievement was Year 12 while for HIV-/? men it was tertiary diploma or trade certificate (P < 0.0001 by MWT).

HIV-/? men were significantly more likely to report having at least one university degree (32%) than HIV+ (18%; OR= 2.19; 95%CI: 1.42 to 3.40; P = 0.004 by FET). Both of these rates are, however, markedly higher than the 10% likelihood of having a university degree for adult males in the general SA community (OR = 1.92; 95%CI: 1.32 to 2.79; P = 0.0009 by Chi squared cf HIV+ men and OR = 4.20; 95%CI: 3.37 to 5.25; P<0.0001 by Chi squared cf HIV-/? men in C&PP).(Australian Bureau of Statistics, 2002a) Men in the cohort overall had a significantly lower likelihood of having a university degree (27%), however, than men in the WHDS (35%, OR: 0.710, 95%CI: 0.510 to 0.999, P = 0.047 by FET).(Griffith *et al.*, 2001)

33% of men in the Periodic had attended university. This rate is not significantly different from the 27% overall rate in the Programme cohort. It is significantly higher than the rate for HIV+ cohort members (OR = 2.22; 95%CI: 1.45 to 3.40; P = 0.0003 by FET), but not significantly different from the rate for HIV-/? cohort members, analysed separately.

# Religion

51% of participants described themselves as atheist, agnostic or having no religion. This characteristic was not significantly different on the basis of HIV status but was very much higher than the rate of 23% among males in the general South Australian community (OR= 3.60; 95%CI: 3.04 to 4.26; P<0.0001 by Chi-squared).(Australian Bureau of Statistics, 2002a)



Of those members of the cohort who identified adherence to a religion, 77% belonged to a Christian religion. This characteristic was also not different when HIV+ and HIV-/? men were compared. The rate was, however, substantially lower than that in the general SA community where 96% of males who had a religious belief were Christian (OR = 0.148; 95%CI: 0.111 to 0.198; P<0.0001 by Chi squared).(Australian Bureau of Statistics, 2002a) In the cohort, 6 men (1%) described themselves as Muslim, 16 (3%) as Buddhist and 38 men (7%) chose 'other non-Christian'. The Periodic did not enquire about the religious beliefs of its respondents,(Van de Ven *et al.*, 2000) but 40% of the people with HIV in Futures II 'indicated that they were atheist/agnostic'.(Grierson *et al.*, 2000 16)

# Heterosexual marriage

111 men in the cohort (20%) had ever been married to a woman and 8 (1%) had been in a de facto relationship with a female partner.

This characteristic was not significantly different between HIV+ and HIV-/? participants. It was however dramatically lower than the rate for SA males of comparable age in the general community of whom 81% have ever been married (OR = 0.117; 95%CI: 0.098 to 0.140; P<0.0001 by Chi squared).(Australian Bureau of Statistics, 2002a) It was also much lower than the rate among males in the WHDS (75%, OR: 0.0843, 95%CI: 0.0584 to 0.122, P < 0.0001 by FET).(Griffith *et al.*, 2001) This characteristic was not recorded in either Futures or the Periodic Survey.(Grierson *et al.*, 2000; Van de Ven *et al.*, 2000)





## Children

104 (19%) of the 542 homosexually active men enrolled into the cohort had children. HIV+ men were significantly less likely to have children than HIV-/? (14% cf 22%; OR= 0.587; 95%CI: 0.361 to 0.953; P = 0.038 by FET).

18 men (3% of the cohort) had children living with them and this characteristic did not differ significantly on the basis of HIV status. The rate was however very much lower than in the general South Australian community where 71% of men of comparable age have children living with them (P<0.0001 by Chi squared).(Australian Bureau of Statistics, 2002a)

The Periodic did not record this characteristic.(Van de Ven *et al.*, 2000) In Futures II 9.0% of respondents reported having 'dependant children' but this was not broken down by gender of the respondent.(Grierson *et al.*, 2000)

# Preferred gender of partners

In response to the question 'Do you enjoy having sex with men, women or both?', men in the C&PP cohort reported predominantly same sex preference.

445 respondents (82%) said they enjoyed sex only with men and a further 59 (11%) reported enjoying sex with 'mostly men'. Thus, 93% of men enjoyed sex with males more than with females.

20 (4%) enjoyed sex with men and women equally and only 6 (1%) reported enjoying sex mostly with women. A further seven men reported enjoying sex with 'no one', and five did not respond to the question.

There was no significant difference in the pattern of gender preference between HIV+ and HIV-/? participants. This question was not asked in either Futures II or the Periodic.(Grierson *et al.*, 2000; Van de Ven *et al.*, 2000)

#### Sex with female partners

In keeping with the data on preferred gender of partners, members of the cohort reported little recent heterosexual activity. 31 men (6%) reported any sex with a female partner or partners in the six months prior to enrolment. Only 7 (1%) reported sex with more than one woman. Three men failed to answer the question.

There was no significant difference in this characteristic on the basis of HIV status but the likelihood was significantly lower than for men in the Periodic where 10% of respondents reported sex with a female partner or partners in the prior six months (OR = 0.553; 95%CI: 0.344 to 0.890; P = 0.016 by FET).(Van de Ven *et al.*, 2000) The analysis of gender of partners in Futures II was complex since the respondent sample included women and significant numbers of heterosexual men.(Grierson *et al.*, 2000) Consequently, comparisons cannot easily be drawn on this characteristic.

The ASHR provides a general Australian community comparator for these characteristics.(deVisser *et al.*, 2003a) Among the men in this study, 9728 provided complete information about sexual partners, and of these 87.9% reported sex with a female partner in the prior *year*. Among the 9469 heterosexually-identified men in the study 89.6% reported sex with female partners in that period, for the 89 bisexually-identified men the rate was 64%, and for the 154 homosexually-identified men it was quite close to the six month rate reported in the C&PP cohort at 4.9%.

# Male sexual partners

There was wide variation in the number of male partners with whom participants reported having had sex in the six months prior to enrolment. 433 men (80%) had been homosexually active in the six months prior to joining the Programme. 87 respondents (16%) reported sex with more than 10 men and 22 (4%) with more than 50 men. The median number of male partners was '2 – 5'.

These rates were not significantly different on the basis of HIV status and there was no significant difference between the cohort responses and those in the Periodic.(Van de Ven *et al.*, 2000)

This characteristic was not recorded in Futures II.(Grierson et al., 2000)

Among the 9578 unselected Australian males who gave complete information for this characteristic in the ASHR, only 1.9% reported any sex with males in the *year* prior to the study, less that 0.6% reported sex with more than nine<sup>\*</sup> partners and 0.1% reported sex with more than 49 partners.(Grulich *et al.*, 2003b) Among the 9355 heterosexually-identified men in that sample, only 0.2% reported any sex with males in the prior year, <0.1% reported sex with more than nine partners and none reported sex with more than 49 partners.

Among the 154 men in that study who identified as homosexual, 80% reported any sex with males in the prior year (the same proportion as in the C&PP cohort), 26% reported sex with more than nine male partners and 6% reported sex with more than 49 men; while of the 89 bisexually-identified men, 49% reported any sex with males in the prior year, 5% reported sex with more than nine men and none reported sex with more than 49 partners.

Although men in the cohort were equally likely to have been homosexually active as the homosexually-identified men in ASHR, they were significantly less likely to have had sex with more than ten male partners than ASHR 'homosexuals' were to have had sex with more than nine (16% vs 26%, OR: 0.545, 95%CI: 0.356 to 0.835, P = 0.0064 by FET). If it is can be assumed that report of more than ten and more than nine partners are not materially different, this may indicate that the C&PP cohort, while no less homosexually active, may be a little less polygamous than randomly selected homosexually active men.

<sup>&</sup>lt;sup>\*</sup> Please note than these classifications differ slightly from those in the C&PP cohort because of slightly different question structure.

This difference could, however, be a regional artefact. Since the ASHR was population weighted, a high proportion of homosexually-identified men would have resided in metropolitan Sydney and Melbourne. Anecdotally, high-level polygamy is more culturally supported among gay men in these cities than in Adelaide. Thus the difference may be related not to a real difference between the cohort and homosexually active men in the South Australian community more generally, but rather to a difference between South Australian homosexually active men and those in larger metropolitan centres.

# Gay community involvement

In an attempt to measure involvement in a gay community, participants were asked about the number of 'gay friends' they had and the proportion of time spent with them. These questions were derived from the Sydney Gay Community Periodic Survey questionnaire.(Van de Ven *et al.*, 1997)

Men enrolled in the Programme appear to have been reasonably highly involved with other gay people. All but nine (98%) reported having at least 'a few' gay friends and 79% reported more than 'a few'. Participants did not differ in this characteristic on the basis of HIV status.

96% of participants spent at least 'a little' time with gay friends and 71% spent more time than 'a little'. There was a trend toward HIV+ men spending more time with gay friends than the remainder of the cohort (P = 0.056 by MWT).



These results differ in an interesting way from those of respondents in the Periodic.(Van de Ven *et al.*, 2000) While homosexually active men in the Care and Prevention Programme cohort report having a higher proportion of gay friends (median 'most' cf 'some', P = 0.047 by MWT), they report spending a significantly *smaller* proportion of their time with gay friends (P = 0.010 by MWT). The latter difference was accounted for almost entirely by HIV+ cohort members (P = 0.001 by MWT), while HIV-/? men did not differ significantly in this characteristic from men in the Periodic (P = 0.155 by MWT). These results may reflect a reduced financial capacity to socialise among the relatively socially-disadvantaged HIV+ participants in the cohort, and raises questions about the validity of these questions as surrogates for 'gay community attachment' in the previous social research. The Periodic did not collect income data but, as has been pointed out, a significantly lower proportion of C&PP cohort members were employed than men in the Periodic.

Futures II did not explore questions of gay community involvement.(Grierson *et al.*, 2000)

# Male relationships

Exactly half of the men in the cohort (271) reported being in a regular relationship with one other man at the time of enrolment. Of these respondents:

- 144 (53%) believed that their relationship was monogamous
- 77 (28%) reported that both partners had sex outside the relationship
- 33 (12%) reported that *they* had sex outside the relationship but believed that their partner did not
- Only 5 (2%) reported that *their partner* had sex outside while they did not.

The marked difference between the last two frequencies is interesting. If it can be assumed that either partner of a 'differentially-monogamous' couple were equally likely to have enrolled in the Programme – and this does not seem unreasonable – the results suggest a discrepancy in some relationships between beliefs about a partner's monogamy and his actual behaviour.

12 men (4% of men in a relationship and 2% of the cohort) reported being in a regular relationship with more than one man.

No significant difference in prevalence of monogamy or polygamy was seen when HIV+ and HIV-/? men with a regular partner were compared.

Respondents in the Periodic were more likely to have a regular male partner (61% cf 50%, OR = 1.52; 95%CI: 1.18 to 1.95; P = 0.0012 by FET).(Van de Ven *et al.*, 2000) 57% of coupled men in the Periodic reported that they believed that their relationship was monogamous and this proportion was not significantly different from the 53% in the C&PP cohort.

Of gay and bisexually identified men in Futures II, approximately 46% appear to have been in a regular relationship (though the gender of partner was not separately identified).(Grierson *et al.*, 2000) Absolute numbers were not provided in the report and so the significance of the apparently slightly lower rate cannot be determined.

As a comparison with primary relationships in the general community, among 7141 men in regular heterosexual relationships in the ASHR, 96.1% 'expected their [female] partner should not have sex with other people', while 94.4% expected that 'they would not themselves have sex with other people'.(Rissel *et al.*, 2003 127-128) This question in ASHR addressed 'expectations' while C&PP questions asked about 'beliefs' about the monogamy of relationships. While it appears likely than polygamy is more widespread among homosexually active men in regular relationships than men in the general community, it should be recognised that this apparent difference could be accounted for in part by different cultures of honesty about polygamy in the two groups.

Among the 6534 men who had been in a regular relationship for at least a year in the ASHR 4.9% overall reported actually having had sex with a person other than their regular partner during the prior year, but among people under 20 this rate was 21.4% and in people between 20 and 29 the rate was 9.6%.

#### **Duration of relationship**

60% of men who had a regular sexual partner at enrolment had been in that relationship for more than two years (162 men). There was no difference in relationship duration on the basis of HIV status. There was, however, a trend toward relationships of longer duration (>2 years) being less likely to be perceived as monogamous (49% vs 60%; OR: 0.644; 95%CI: 0.394 to 1.053; P = 0.0837 by FET).

Although more men in the Periodic were in a regular male relationship, that relationship was more likely to be of short duration (32% < 1 year cf 20% in Programme cohort; OR = 1.97; 95%CI: 1.32 to 2.95; P= 0.001 by FET).(Van de Ven *et al.*, 2000) This characteristic was not reported in Futures II.(Grierson *et al.*, 2000)

# Sexual behaviour with a regular partner

The C&PP's enrolment questionnaire concerning sexual behaviour was based on that developed by the National Centres for HIV Epidemiology and Clinical Research and HIV Social Research for the first Sydney Gay Community Periodic Survey.(Van de Ven *et al.*, 1997) It asked participants to differentiate between their sexual activities with a regular partner, where there was one, and those with casual partners. The Programme database allows correlation of sexual behaviour with HIV status of the participant and the believed HIV status of the regular partner.

312 men (58%) described sexual activity with at least one regular male partner in the six months prior to enrolment. This characteristic was not significantly different between HIV+ (59%) and HIV-/? (57%) participants.

This is not quite significantly lower than the corresponding proportion in the overall figures of the (1999 Adelaide) Periodic (64%; OR = 0.780; 95%CI: 0.605 to 1.006; P = 0.061 by FET).(Van de Ven *et al.*, 2000) In the Periodic report this characteristic was further analysed by recruitment site. It is of interest that the proportion of men reporting sex with a regular partner in the C&PP cohort is significantly higher than the 37% among men in the Periodic recruited at gay venues (OR = 2.30; 95%CI: 1.72 to 3.08; P<0.0001 by FET) and significantly lower than the 70% among men recruited at Picnic in the Park (OR = 0.571; 95%CI: 0.430 to 0.758; P = 0.0001 by FET). Picnic in the Park is a gay community event that is often attended by gay couples, while gay men in search of a partner often attend the venues. The C&PP cohort's rate is between these two, which may indicate that, in comparison with the two Periodic Survey settings, its sampling is relatively independent of regular partnership status.

The rate among HIV+ participants in the Programme is significantly higher than that among homosexually active (positive) men in Futures II, of whom 47% report sex with a regular partner in the prior six months. (OR = 1.60; 95%CI: 1.15 to 2.23; P = 0.0049 by FET).(Grierson *et al.*, 2000)



For the purpose of this analysis, the 312 men who recounted sex with a regular partner have been divided according to their own and their partner's reported HIV status (positive [+], negative [-] or unknown [?]).

Since both members of some couples have enrolled in the Programme, some relationships will appear twice in this breakdown, once 'from each side'. Coupling between participants is not identified in the database and so the extent of this kind of double counting cannot be determined.

Since what is being studied in the analysis that follows is the relationship between a particular man's sexual behaviour and *his beliefs* about his own and his partner's status, this should not present a particular problem.



The distribution of couple types was different from that seen in the Periodic, which had fewer HIV positive respondents and thus fewer +/x' couples.

For the remainder of this analysis, +/+ and -/- couplings will be referred to as 'HIV concordant', +/- and -/+ as 'HIV discordant' and the term 'HIV non-concordant' will be used to include +/- and -/+ together with couplings where the status of either partner was unknown to the participant.

Participants were asked, by means of sexually-explicit plain language, to identify whether they had engaged in any of a number of activities, with one or more regular sexual partners, in the preceding six months: 'never', 'occasionally' or 'often'. For the purposes of this analysis, both affirmative responses have been grouped together.

The sexual activities listed included:

- 1. Receptive oral sex without ejaculation\*
- 2. Receptive oral sex with ejaculation<sup>\*</sup>
- 3. Insertive anal sex with a condom
- 4. Receptive anal sex with a condom
- 5. Insertive anal sex without a condom
- 6. Receptive anal sex without a condom

# Receptive oral sex with a regular partner

Receptive oral sex without ejaculation was the most popular activity reported with regular partners, with 250 participants (80% of those men with regular partners) engaging in it. This frequency was not different between HIV+ and HIV-/? respondents, and was not recounted in either the Periodic or Futures II.(Grierson *et al.*, 2000; Van de Ven *et al.*, 2000)

Receptive oral sex *with* ejaculation was reported by 118 men (38% of those with regular partners) and there was a trend towards HIV+ participants being more likely to engage in this practice with a regular partner than HIV-/? (45% vs 35%; OR = 1.56; 0.97 to 2.52; P = 0.0840 by FET), but interestingly there was no difference between participants with HIV concordant versus HIV non-concordant partners in this characteristic.

Receptive fellatio with ejaculation was practiced in this setting by 45% of men with regular partners in the Periodic and this rate is not significantly different from that of the cohort.(Van de Ven *et al.*, 2000) Futures II did not report this behaviour.(Grierson *et al.*, 2000)

<sup>\*</sup> Insertive oral sex was not included in the original Sydney Gay Community Periodic Survey, and so was not asked about in the questionnaire.(Van de Ven *et al, 1997*)

#### Any anal sex with a regular partner

234 participants (75% of those with regular partners) had had some kind of anal sex with that partner in the six months before enrolment. This was not significantly different on the basis of the HIV status of the respondent, but participants with HIV concordant partners were significantly more likely to report this activity than those with HIV non-concordant partners (81% vs 69%; OR = 1.87; 95%CI: 1.11 to 3.15; P = 0.0259 by FET).

Men with regular partners in the Periodic were significantly more likely to have had anal sex within the relationship in the prior six months (86%) than such men in the cohort (OR = 2.12; 95%CI: 1.39 to 3.22; P = 0.0005 by FET).(Van de Ven *et al.*, 2000) Comparison data could not be discerned from the Futures II report due to data aggregation.(Grierson *et al.*, 2000)

#### Insertive anal sex with a regular partner

190 men (61% of those with regular partners) reported having had insertive anal sex in that setting in the six months before enrolment. Again, there was no significant difference in this characteristic between HIV+ and HIV-/? participants, but those men with an HIV concordant regular partner were significantly more likely to report the activity than those whose regular partner was HIV non-concordant (69% vs 53%; OR = 2.03; 95%CI: 1.28 to 3.23; P = 0.0036 by FET).

Men with regular partners in the Periodic were significantly more likely to report having had insertive anal sex within the relationship in the prior six months (76%) than men in the cohort (OR = 2.02; 95%CI: 1.42 to 2.86; P< 0.0001 by FET).(Van de Ven *et al.*, 2000) The role taken in anal sex was not reported in Futures II.(Grierson *et al.*, 2000)

#### Receptive anal sex with a regular partner

173 participants (55% of those with regular partners) reported receptive anal sex with that partner in the six months before enrolment. No significant difference in this characteristic was seen on the basis of the HIV status of the respondent or the seroconcordance of the couple.

The rate of this activity reported in the Periodic (67%) was significantly higher than that seen in the cohort (OR = 1.632; 95%CI: 1.17 to 2.27; P = 0.0036 by FET).(Van de Ven *et al.*, 2000)

#### Any unprotected anal sex with regular partner

161 enrolees (52% of those with regular partners) reported unprotected anal intercourse with a regular partner (UAI-R), at least occasionally, in the six months prior to joining the Programme. This did not differ significantly between HIV+ and HIV-/? respondents and, interestingly, the rate of 52% is identical to the proportion of men with partners who reported the activity in the Periodic.(Van de Ven *et al.*, 2000)

The rate among HIV+ men in the cohort (48%) was lower than the rate among (positive) men with a regular male partner in Futures II (56%) to an extent that approaches statistical significance (OR = 0.648; 95%CI: 0.419 to 1.002; P = 0.0576 by FET).(Grierson *et al.*, 2000)

Men with an HIV concordant regular partner were significantly more likely to have had UAI-R than men whose partners were non-concordant (67% vs 36%; OR = 3.68; 95%CI: 2.30 to 5.87; P < 0.0001 by FET). It is of considerable concern, however, that even among the 78 participants who *knew* their regular partner to be HIV *discordant*, 19 (24%) reported having had unprotected anal intercourse with him in the prior six months.



A similar relationship between HIV status concordance and unprotected sex with regular partners was seen in the Periodic.(Van de Ven *et al.*, 2000) The number of men whose serostatus was different from their partners (or where the status of either person was unknown) was small in that study, however. In Futures II the relationship between seroconcordance and reported unprotected anal intercourse was more pronounced than in the C&PP cohort.(Grierson *et al.*, 2000) 84% of men with HIV concordant male partners in Futures II reported UAI-R compared with 67% of similar men in the C&PP cohort (OR = 2.50; 95%CI: 1.39 to 4.49; P = 0.0022 by FET). Interestingly, the rate of UAI-R among male respondents with HIV non-concordant male partners in Futures II (34%) was about the same as that in the cohort (36%).

#### Unprotected insertive anal sex with a regular partner

128 participants (41% of those with regular partners) had had unprotected insertive anal sex with that partner in the six months before enrolment. There was a trend toward HIV+ men with regular partners overall being less likely (33%) to report this activity than HIV-/? men (45%; OR = 0.609; 95%CI: 0.374 to 0.990 P = 0.0523 by FET).

Men who believed their partner to have a concordant HIV status with their own were much more likely (56%) than other men with regular male partners to report this behaviour (26%; OR = 3.75; 95%CI: 2.33 to 6.06; P<0.0001 by FET).

Insertive and receptive unprotected intercourse were not differentiated in the reports of either the Periodic or Futures II.(Grierson *et al.*, 2000; Van de Ven *et al.*, 2000)

#### Unprotected receptive anal sex with a regular partner

118 cohort members (38% of those with regular partners) reported having had unprotected receptive anal sex in this setting at least occasionally during the six months before enrolment. HIV+ and HIV-/? participants did not differ significantly in this regard.

Men with HIV concordant regular partners were significantly more likely to report having engaged in this activity than men with HIV non-concordant partners (50% vs 26%; OR = 2.90; 95%CI: 1.80 to 4.67; P < 0.0001 by FET).

#### 'Strategic Positioning'

Van de Ven, Kippax and colleagues have described the notion of 'strategic positioning' among male couples, where HIV+ men may be more likely to take a receptive rather than an insertive role in anal intercourse in the belief that this will reduce the risk of transmission.(Van de Ven *et al.*, 2002)

There is some suggestion that this phenomenon may have been occurring in the cohort on enrolment.

Among the 70 non-concordant couples where the participant was known to be HIV+ and his partner was not, only 9 (13%) reported UAI-R with the (HIV+) participant inserting, while for the 30 non-concordant couples where the partner was known to be HIV+ and the participant was not, 11 (37%) reported UAI-R with the (HIV-/?) participant inserting (OR = 0.255; 95%CI: 0.092 to 0.707; P = 0.0123 by FET).

Similarly, among the 70 non-concordant couples where the participant was known to be HIV+, 19 (27%) reported UAI-R with the (HIV+) participant *receptive* compared with only 5 of the 30 non-concordant couples (17%) where the partner was known to be HIV+ (though this second difference is not statistically significant).



A possible alternative explanation, that men who prefer receptive anal intercourse are more likely to be HIV infected, is not supported by data. HIV+ participants in the cohort were no more likely to engage in receptive anal intercourse *per se* or in unprotected receptive anal intercourse. The difference in frequency was only apparent between regular partners when the HIV status of *both* parties was taken into account.

#### General community comparison

52% of all participants with regular partners and 67% of those who believed their partner to share their HIV status reported unprotected anal intercourse in the six months prior to enrolment. As a comparison, among the 6845 males in the ASHR with regular female partners, 88.2% reported unprotected vaginal intercourse with that partner during the six months before the survey.(deVisser *et al.*, 2003b) Thus, coupled men in the cohort were less likely than Australian men generally to engage in unprotected intercourse with their regular partner, even when they believed that person to share their HIV status.

# Sexual behaviour with casual partners

358 of the 542 participants in the C&PP (66%) reported having had sex with a casual male partner in the six months before enrolment, with no significant difference in rate observed on the basis of HIV status.

The rate is not significantly different from the 62% of men in the Periodic who reported this activity.(Van de Ven *et al.*, 2000) 59% of homosexually and bisexually identified men in Futures II reported sex with a casual male partner in the prior six months, which is lower than the corresponding rate among HIV+ men in the cohort (67%) to an extent that approaches statistical significance (OR = 0.708; 95%CI: 0.503 to 0.996; P = 0.0515 by FET).(Grierson *et al.*, 2000)

By way of comparison, among the 8551 Australian men in the ASHR who had been heterosexually active at all in the prior year,(deVisser *et al.*, 2003a) 601 (7.0%) reported vaginal intercourse with a casual partner in the six months before the survey.(deVisser *et al.*, 2003b)

### Receptive oral sex with casual partners

Receptive oral sex was again the most popular of the activities about which participants were asked, with 297 men (83% of those who had casual sex at all) engaging in it.<sup>\*</sup> For 111 participants (31% of the 358 men who had casual partners), receptive oral sex with a casual partner included ejaculation in the mouth at least occasionally.

The frequency of these activities did not differ significantly between HIV+ and HIV-/? enrolees. Nor was the frequency of receptive fellatio with ejaculation significantly different from that in the men from the Periodic who reported sex with casual partners (41%).(Van de Ven *et al.*, 2000) Futures II did not report oral sexual activity.(Grierson *et al.*, 2000)

<sup>\*</sup> As was the case with regular partners, information about insertive oral sex was not sought in the questionnaire.

#### Any anal sex with casual partners

242 participants (68% of men who reported any casual sex) had engaged in anal sex of some kind with a casual partner in the six months before enrolment. There was no significant difference in this characteristic on the basis of HIV status.

There was also no significant difference in the frequency of the activity in this cohort from that among men in the Periodic who reported casual sex (72%).(Van de Ven *et al.*, 2000) Comparison data could not be discerned from the Futures II report due to aggregation.(Grierson *et al.*, 2000)

#### Insertive anal sex with casual partners

194 participants (54% of the men who had had casual sex) reported having engaged in this activity. This rate was not significantly different from the frequency of 61% in the Periodic and there was no difference on the basis of HIV status.(Van de Ven *et al.*, 2000) The role taken in anal sex was not reported in Futures II.(Grierson *et al.*, 2000)

#### **Receptive anal sex with casual partners**

176 participants (49% of the men who reported casual sex) had engaged in receptive anal intercourse with a casual partner in the six months before enrolment. This rate did not vary significantly from the rate of 55% of men who had casual partners in the Periodic.(Van de Ven *et al.*, 2000)

HIV+ members of the cohort were significantly more likely to include this activity in their sex with casual partners (59%) than HIV negative (44%; OR = 1.87; 95%CI: 1.20 to 2.91; P = 0.0055 by FET).

#### Unprotected anal sex with casual partners

86 men who enrolled in the cohort included unprotected anal intercourse (UAI-C) in their sexual activity with casual partners at least occasionally. This represents 17% of all participants and 24% of those who reported sex of any kind with casual partners in the six months prior to enrolment. Neither of these rates differ significantly from those reported in the Periodic (12% and 20% respectively).(Van de Ven *et al.*, 2000)

Among HIV+ participants who had casual sex, the rate of UAI-C was 27% while for HIV-/? it was 22%. While these frequencies are not significantly different, they follow a similar pattern to the rates of 32% and 19%, respectively, among positive and negative/unknown status men in the Periodic who had sex with casual partners.

The frequency of any insertive UAI-C was 16% among men in the C&PP cohort who had casual sex while that for receptive UAI-C was 18%. The rate for insertive intercourse did not differ significantly on the basis of HIV status, but HIV+ participants were significantly more likely to report unprotected receptive anal sex than HIV-/? (21% vs 12%; OR = 1.90; 95%CI: 1.06 to 3.41; P = 0.0316 by FET).

### General community comparison

By way of comparison, among the 601 men in the ASHR who reported any sex with casual female partners in the prior six months, 430 (55%) reported having engaged in unprotected vaginal sex on at least one occasion.(deVisser *et al.*, 2003b) Thus, more than twice the proportion of men in the general community who have casual sex engage in unprotected intercourse compared with such men in the cohort.

The biopsychosocial correlates of UAI-R with a non-concordant partner and of UAI-C are discussed in Part 3 (see page 366).



# Anthropometrics

#### Height

The median height of C&PP participants was 177cm. Height was not normally distributed in this cohort (Kolmogorov-Smirnov distance (KS) = 0.06; P = 0.0333). The median height of the sample is slightly, but significantly, shorter than the median height of South Australian males aged over 18 years in the NHS01 (178.0 cm; P = 0.038 by one sample Wilcoxon Signed Ranks Test [WSRT]).(Australian Bureau of Statistics, 2002d) No explanation for this difference was apparent to the researchers and it may be a chance finding. There was no significant difference in height between HIV+ and HIV-/? participants in the cohort (median HIV+ = 177.5cm, HIV-/? = 176.0 cm; P = 0.251 by MWT).

## Weight

The median weight of men in the cohort was 75.3kg. Weight was also not normally distributed across the group (KS = 0.09; P = 0.0007). The median weight is significantly lower than that of SA adult males in the general community in the NHS01 (83.0 kg, P<0.0001 by one sample WSRT).(Australian Bureau of Statistics, 2002d)

HIV+ men in the cohort (median weight = 73.0kg) were significantly lighter than HIV-/? men (median weight = 77.6; P = 0.0003 by MWT). HIV+ men did not account for all of the whole cohort's difference from the population norm however, since the median for HIV-/? men was still significantly lower than the median for SA males when analysed separately (P = 0.0256 by one sample WSRT).

## **Body mass index**

Body mass index (BMI) is a measure of weight for height whose invention is attributed to Belgian mathematician Lambert Quetelet.(Daniels *et al.*, 1997) It is calculated from the following equation:

 $BMI = (Weight in kg) / ((Height in metres)^2)$ 

The median BMI of men in the cohort was near the upper limit of the ideal range at 24.4 kg/m<sup>2</sup>.

The median for HIV+ men (23.5 kg/m<sup>2</sup>) was significantly lower than that of HIV-/? (24.8 kg/m<sup>2</sup>; P = 0.0001 by MWT).

231 men (43%) had a BMI greater than 25 kg/m<sup>2</sup> indicating the presence of overweight or obesity. 50 participants (9%) had a BMI in the obese range (above 30 kg/m<sup>2</sup>). HIV+ men (32%) were significantly less likely than HIV-/? men (49%) to be overweight or obese (P = 0.0002 by FET).

Even HIV negative men, however, had a somewhat lower likelihood of being overweight or obese than either the 52% chance among adult males in the general South Australian community, (McLennan *et al.*, 1998) or the 59% chance among males attending GPs in the BEACH Study. (Bayram *et al.*, 2003)



#### **Triceps skin fold**

The mean triceps skin fold (TSF) measurement in the cohort was 15.6mm, which approximates the  $50^{\text{th}}$  centile (15mm) for American males of the median height of the cohort in the standard reference tables.(Frisancho, 1984) HIV+ men had a significantly lower median thickness (10mm) than HIV-/? men (15mm, P<0.0001 by MWT). This association with HIV status remained significant when controlling for age, height and weight in multivariate analysis.

#### Mid-arm muscle circumference

The median circumference at mid upper arm for the cohort was 310 mm. The median for HIV+ men (300mm) was significantly lower than that for HIV-/? participants (310mm, P = 0.0001 by MWT). The Mid-Arm Muscle Circumference (MAMC) is calculated according to the following formula:

```
MAMC = Mid arm circumference - (Pi x TSF)
```

The median MAMC in the cohort was 259mm. The median for HIV+ men was not significantly different from that of HIV-/?. MAMC was significantly correlated with BMI (Pearson r = 0.504; 95%CI: 0.438 to 0.565; P < 0.0001). These findings suggest that the observed differences in simple mid arm circumference were related to fat mass or distribution rather than a difference in muscle mass. The MAMC of the cohort is significantly lower from that of a sample of 5261 American males aged 18 - 74 on the standard tables for this test (280mm, P < 0.0001 by t-test with Welch's correction).(Bishop *et al.*, 1981) One may speculate about the reason for this difference but one possibility would relate to the smaller proportion of participants in the Programme who are employed in manual occupations than in most population samples.

### **Abdominal girth**

The median abdominal girth of men in the cohort was 90cm. HIV+ men had a significantly lower median (87cm) than HIV-/? (92cm, P <0.0001 by MWT).

Abdominal girth at enrolment was also independently correlated with weight, height, older age and triceps fold thickness. In multivariate analysis, no association with HIV status remained when these variables had been accounted for.

#### **Blood pressure**

The median blood pressure of the cohort was 120/80 mmHg. HIV+ men had significantly lower systolic (mean 121, median 120 vs mean 125, median 120; P = 0.0014 by MWT) and diastolic (mean 78, median 80 vs mean 81, median 80; P = 0.0060 by MWT) blood pressure than their HIV-/? counterparts.



In multivariate analysis, however, age was the only independent predictor of blood pressure and the difference could be wholly accounted for by the younger age of the HIV+ group.

51 men enrolled (9%) had systolic blood pressures above 140mmHg indicating systolic hypertension according to the National Heart Foundation guidelines and 49 (9%) had diastolic blood pressures above 90mmHg indicating diastolic hypertension.(National Heart Foundation, 2004, p 10) This is rather lower than the 20.7% of males aged 19 and over with a systolic BP >140 and 13.5% with a diastolic BP >90 in the (Australian) National Nutrition Survey in 1995.(McLennan *et al.*, 1998) There was no significant difference in these proportions when HIV+ and HIV-/? members of the C&PP cohort were compared.

#### Peak expiratory flow rate

Peak expiratory flow rate (PEFR) was measured on 514 men at enrolment. The mean rate was 6.79 litres per second, and the median 6.91. Unlike most anthropometric variables in this cohort, PEFR was normally distributed (KS = 0.05).



Perhaps surprisingly, HIV+ men had a higher PEFR (mean = 7.40 L/sec) than HIV-/? men (mean = 6.46; P = 0.0002 by t-test). This could not be explained by other variables since, in a multivariate model, height, (larger) abdominal girth and (positive) HIV status were all independent predictors of higher PEFR.

The reasons for this association are unclear, though one hypothesis is that HIV+ men would probably have been more likely to have been in recent contact with medical care on enrolment and thus might have been more likely to have had any respiratory conditions such as asthma under treatment than HIV-/? men.

The Australian norms for PEFR, derived from Gibson's sample of 6511 nonsmoking males in 1979, yield a predicted PEFR of a little over 9L/sec for men of the average height and age of cohort members.(Gibson *et al.*, 1979) The flow rates in the cohort are clearly lower than this level, which is probably related, at least in part, to the high rates of smoking seen in the group (see page 299).

# Sexually transmitted infection history

### Syphilis

421 men (78%) had been tested for syphilis prior to enrolment in the Care and Prevention Programme. Of them, 8 individuals (2% of those tested and 1% of the cohort) had serological evidence of previous syphilis. All of these individuals reported having received injected antibiotic treatment. There was no difference in this characteristic on the basis of HIV status.

For the notifiable sexually transmitted infections (STIs) it is possible to estimate the community lifetime prevalence by applying the notified annual incidence multiplied by years of sexually-active life for the population of South Australia. This assumes a constant incidence, uniformity of risk across the sexually active life span and 'capture' of all cases of the disease by the surveillance system. None of these assumptions are likely to be quite true and so the resulting estimate should be regarded as very approximate. The Australian Study of Health and Relationships, reported in 2003, conducted telephone interviews with 19,307 Australians aged 16 to 59, sampled by a modified random digit dialling technique, including 10,173 men and 501 South Australian men.(Smith *et al.*, 2003) It included questions about lifetime history of STIs and can be used to check the result of notification-based calculations.

The mean annual notification rate for syphilis in South Australia between 1971 and 1999 was 154 cases.(STD Control Branch, 1989 - 1999) The average proportion of these notified cases who were male (calculated from the years in which complete data were available) was 47%. This yields an estimated mean notification rate among males of  $153.8 \times 0.47 = 72.3$ .

Based on Australian Bureau of Statistics population by year tables, the population of males in South Australia aged 15 to 65 varied between during this period between 356,125 and 453,902 with a mean of 412,660. Thus the average incidence of syphilis among males in South Australia for this period was 72.3 / 412,660 = 0.1752 per 1000 per annum. The mean age of men in the cohort was 41. South Australian men of this age would have had an average of 41 - 14 = 27 years of sexually active life in which to have acquired syphilis. Thus the predicted population lifetime prevalence for men aged 41 in South Australia is 0.175 x 27 = 4.73 per 1000.

Among men in the ASHR, 0.6% or 6 per thousand are reported to have given a lifetime history of syphilis.(Grulich *et al.*, 2003a) This rate is comparable to that obtained by the calculations described and supports the validity of the method.

Men in the cohort who had been tested for syphilis had a lifetime prevalence of 8/421 = 19 per thousand, or more than four times the calculated population prediction, and more than three times the rate reported by a population sample of Australian males in the ASHR.

#### **Herpes simplex**

240 participants (44%) gave a clinical history of herpes simplex virus infection (HSV) in at least one anatomical site. In 163 men (30% of the cohort) this was orofacial only, in 24 (4%) it was anal only, in 31 (6%) it was genital only and in 22 (4%) it was both 'above and below the waist'.

HIV+ participants were significantly more likely to report having had HSV at all (55% cf 39%; OR = 1.91; 95%CI: 1.33 to 2.74; P= 0.0005 by FET) and also to have had it anogenitally (25% cf 9%; OR = 3.51; 95%CI: 2.13 to 5.76; P<0.0001 by FET) than HIV-/? men.



Herpes simplex is not a notifiable disease in South Australia and so the approach used to estimate the population prevalence of syphilis cannot be employed.

In the ASHR population sample of 10,173 Australian men, 2.1% gave a clinical history of 'genital herpes'.(Grulich et al., 2003a) Post hoc comparison yields an odds ratio of 7.73 (95%CI: 5.96 to 10.03, P < 0.0001 by Chi squared) for men in the C&PP giving a clinical history of anogenital herpes compared with Australian men in the ASHR. For a conservative estimate, a 2x2 table was also calculated counting only the 31 men in the C&PP cohort who specifically reported 'genital herpes'. In this analysis the odds ratio was 2.63 (95%CI: 1.81 to 3.82, P < 0.0001 by Chi squared) for men in the cohort reporting genital herpes compared with male ASHR respondents. When HIV-/? men only were considered (since HIV infection may influence the clinical expression of herpes virus infections) the apparent inequality was somewhat less marked. HIV-/? men had an odds ratio of 4.43 (95%CI: 3.02 to 6.48, P < 0.0001 by Chi squared) of reporting clinical anogenital herpes infection compared with ASHR male respondents reporting 'genital herpes'. In the most conservative analysis, comparing HIV-/? men who reported only a genital herpes history, the odds ratio compared with men in the ASHR falls to 1.62 and is no longer statistically significant.

In a New Zealand survey of people attending for HIV testing in a non-STD clinic setting in the late 1980s, 8% of 561 men (of whom 219, or 39% identified as 'homosexual' or 'bisexual') and 13% of 240 women gave a clinical history of genital herpes.(Chetwynd *et al.*, 1992)

Interestingly, Russell and co-workers found that 39 'homosexual men' out of an Australian general practice sample of 300 (13%, roughly the same as the C&PP overall rate) gave a clinical history of genital herpes *and* were seropositive for antibodies for HSV2.(Russell *et al.*, 2001a)<sup>\*</sup> Saxton and colleagues, however, found that among 1852 homosexually active men who responded to a phone-in survey in New Zealand in 1996, 8% reported a history of clinical anogenital herpes,(Saxton *et al.*, 2002) which is very close to the 9% among HIV-/? men in the cohort.

Since Russell's group reported from a GP site that, like the C&PP, provides HIV clinical care, and Saxton's group reported a non-clinical sample from a population with a low prevalence of HIV, even among homosexually active men, these results conform to what would be expected and support the validity of the C&PP findings.

The data from the C&PP cohort, confirmed by those of Russell's group, suggest that homosexually active men attending for general practice care have a rate of clinical history of genital herpes that substantially higher than that seen among men in the general population, especially if HIV+ men are included in the analysis.

#### Warts

164 C&PP participants (30%) gave a history of anal or genital (or both) warts. In 120 (22% of the cohort) these were anal only, in 31 (6%) genital only and in 13 (2%) both anatomical locations were affected.

<sup>&</sup>lt;sup>\*</sup> Whether there were any men with a clinical history among the HSV2 *seronegative* men in this group cannot be discerned from the paper.

HIV+ participants were more than twice as likely to report a clinical history of anogenital warts than HIV-/? men (47% vs 22%; OR = 3.15; 95%CI: 2.15 to 4.62; P < 0.0001 by FET).



Anogenital wart disease is not notifiable in South Australia and so no data are collected that might be used to calculate local incidence and prevalence.

The population sample of 19,307 Australian men in the ASHR was asked about a history of 'genital warts' and respondents were prompted that this should be taken to include anal warts if they asked.(Grulich *et al.*, 2003a) 4.0% gave such as history. *Post hoc* comparison yields an odds ratio of 10.4 (95%CI: 8.55 to 12.7, P < 0.0001 by Chi squared) for men in the C&PP cohort giving a history of anogenital warts compared with men in the ASHR. Even if HIV+ cohort members are excluded to account for any direct effects of HIV on wart virus expression, HIV-/? men from the cohort still have an odds ratio of 6.69 (95%CI: 5.15 to 8.68, P < 0.0001 by Chi squared) for reporting warts compared with men in the ASHR.

In Bassett's sample of 300 exclusively heterosexually active men attending a sexual health centre in 1985, 51 (17%) gave a history of 'genital warts', though it is not clear if this included report of anal warts.(Bassett *et al.*, 1994)

In Chetwynd's sample of attenders for HIV testing in a non-STD clinic setting in New Zealand in the late 1980s, 10% of 561 men (including 219 who identified as 'homosexual' or 'bisexual') gave a history of 'genital warts', while in Saxton's 1996 phone-in sample of 1852 homosexually active New Zealand men, 216 (11.7%) reported a history of 'anal warts'.(Saxton *et al.*, 2002)

These comparisons suggest that a clinical history of anogenital warts may be more prevalent among homosexually active men attending for primary care than among other men in Australia and New Zealand.

#### Gonorrhoea

171 participants (32% of the cohort) gave a clinical history of gonorrhoea on enrolment into the Programme. In 119 men (22% of the cohort) it had been only urethral, for 12 men (2%) rectal, for 5 men (1%) pharyngeal and an additional 35 (6%) had had the infection at more than one site.



HIV+ men were significantly more likely to report having had gonorrhoea at any site than HIV-/? men (44% vs 26%; OR = 2.05; 95%CI: 1.41 to 2.99; P=0.0002 by FET).

HIV+ men were also more than twice as likely to report rectal or multiple site gonorrhoea than HIV-/? men (13% vs 6%; OR = 2.21; 95%CI: 1.21 to 4.03; P = 0.0145 by FET).

Gonorrhoea is a notifiable infection in South Australia and so the methodology described for syphilis on page 282 can be applied to estimate a lifetime prevalence for South Australian men of the average age of the C&PP cohort. The limitations of this method described previously also apply to this calculation.

The mean annual notification rate for gonorrhoea in South Australia between 1971 and 1999 was 789 cases.(STD Control Branch, 1989 - 1999) The average proportion of these notified cases who were male (calculated from the years in which complete data were available) was 67%. This yields an estimated mean notification rate among males of 789 x 0.67 = 529. Based on Australian Bureau of Statistics population by year tables, the population of males in South Australia aged 15 to 65 rose during this period from 356,125 to 453,902 with a mean of 412,660.(Australian Bureau of Statistics, 2004a) Thus the average incidence of gonorrhoea among males in South Australia for this period was 529 / 412,660 = 1.28 per 1000 per annum. The mean age of men in the cohort was 41. South Australian men of this age would have had an average of 41 - 14 = 27 years of sexually active life in which to have been infected with gonorrhoea. Thus the predicted population lifetime prevalence for men aged 41 in South Australia is  $1.28 \times 27 = 34.59$  per 1000.

2.2 % of males in the ASHR (or 22 per thousand) reported a lifetime history of gonorrhoea.(Grulich *et al.*, 2003a) This estimate is somewhat lower than, but of the same order as, the calculated estimate as so provides some support for the calculation method.

Men in the cohort reported a lifetime prevalence of 171/542 = 315 per thousand. This is more than nine times the calculated population prediction and more than 14 times the prevalence among males in the ASHR (OR: 20.5, 95%CI: 16.7 to 25.2, P < 0.0001 by Chi squared), suggesting significant health inequality with regard to this characteristic experienced by the cohort.
#### **Chlamydia:**

32 men in the cohort (6%) gave a history of prior chlamydial infection on enrolment. Two infections were reported as pharyngeal, two as rectal, one person reported a history of infection at more than one site and the remainder were urethral. HIV+ men were significantly more likely to report prior chlamydia than HIV-/? (9% vs 4%; OR = 2.33; 95%CI: 1.14 to 4.78; P = 0.0215 by FET).

Chlamydia is also a notifiable disease and so the method for estimating lifetime prevalence described for syphilis on page 282 can be applied, except that chlamydia only became notifiable in 1989 and very little testing was undertaken before that date. Thus men of the average age of the cohort in 1999 would only have had ten years during which they might have been diagnosed with chlamydia, compared with 27 years for gonorrhoea or syphilis, and this needs to be taken into account in the calculations.

The mean annual notification rate for chlamydia in South Australia between 1989 and 1999 was 1034 cases.(STD Control Branch, 1989 - 1999) The average proportion of these notified cases who were male (calculated from the years in which complete data were available) was 36%. This yields an estimated mean notification rate among males of  $1034 \times 0.36 = 372$ . Based on Australian Bureau of Statistics population by year tables, the population of males in South Australia, aged 15 to 65 varied between during this period between 436,272 and 453,902 with a mean of 438,613. Thus the average incidence of chlamydia among males in South Australia for this period was 372 / 438,613 = 0.849 per 1000 per annum. As discussed, South Australian men of this age would have had an average of 10 years of sexually active life during which they might have been diagnosed with chlamydia. Thus the predicted population lifetime prevalence for men aged 41 in South Australia is 0.849 x 10 = 8.49 per 1000.

The rate of reporting a chlamydia history among men in the ASHR was 17 per thousand, or about twice the population rate predicted by this method.(Grulich *et al.*, 2003a) This difference is substantial and tends to undermine the validity of calculation technique and the assumptions used to estimate it.

Men in the cohort reported a lifetime prevalence of 32/542 = 59.0 per thousand. Even if the higher ASHR rate is used as the comparator, there still appears to be a more than three fold greater lifetime prevalence among men in the C&PP cohort than Australian males in the ASHR (OR: 5.35, 95%CI:3.67 to 7.81, P < 0.0001 by Chi squared).

#### Non-specific urethritis (NSU):

28% of participants (153 men) reported a clinical history of NSU. HIV+ men were significantly more likely to give this history than HIV-/? men (33% vs 25%; OR = 1.49; 95%CI: 1.01 to 2.20; P = 0.0445 by FET).

NSU is not a notifiable diagnosis which precludes the possibility of direct population prevalence estimation. 5.0% of the 19,307 males in the ASHR reported this history yielding an odds ratio on *post hoc* calculation of 7.48 (95%CI: 6.13 to 9.11, P < 0.0001 by Chi squared) for men in the cohort reporting the history compared with them.(Grulich *et al.*, 2003a)

In Chetwynd's sample of attenders for HIV testing in a non-STD clinic setting in New Zealand in the late 1980s, 20% of 561 men (including 219 who identified as 'homosexual' or 'bisexual') gave a history of 'NSU'.(Chetwynd *et al.*, 1992) It should be recognised, however that Chlamydia testing was not in widespread use at the time of this study and it is likely that a proportion of people reporting NSU would in fact have experienced chlamydial infection for which there was at the time no diagnostic test. The same is true of Bassett's Sydney STD clinic sample from 1985, where 136 (45%) of 300 exclusively heterosexually active men gave a lifetime history of 'non-gonococcal urethritis'.(Bassett *et al.*, 1994)

#### Any sexually transmitted infection:

505 of the 542 homosexually active men in the cohort (93%) gave a history of at least one of the STIs discussed in this section (excluding orofacial herpes). There was no significant difference in this characteristic on the basis of HIV status.

20.2% of the 19,307 men in the ASHR gave a history of any STI. This figure included 9.8% of the cohort who reported pubic lice, as well as small numbers of people who reported hepatitis A or hepatitis B. Thus, this rate is probably higher than would have been obtained by including only the conditions discussed in this section, but this cannot be discerned from the published data. As a result, the more than four fold apparent difference in this characteristic between men in the cohort and Australian men in the ASHR would be expected to be somewhat of an *under estimate* of the true health inequality between the groups with regard to this characteristic.

## Depressive disorders

The Prime-MD screening tool (Spitzer *et al.*, 1994) was administered to all participants on enrolment into the C&PP. The instrument includes two screening questions that ask about the presence of depressed feelings or reduced interest and pleasure in activities. If either of these questions were answered affirmatively, a full set of questions about depressive symptoms was asked.

The tool identifies the presence of either Major Depressive Episode (MDE) or Dysthymic Disorder (DD), or both, according to the criteria laid down in the Fourth Edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV).(American Psychiatric Association. Task Force on DSM-IV, 1994) MDE describes serious clinical depression while DD is a less intense condition of depressed mood, which, none-the-less, has been present and significantly impacted on function on the majority of days in the preceding two years.

Further questions identify the presence of an MDE at an earlier time in the person's life.

The cross-sectional prevalence of depressive disorders was very high in the C&PP cohort on enrolment. 161/542 men (30%) met the criteria for MDE at the time of enrolment. 144 men (27%) were diagnosed with current DD on enrolment. These rates include a cross over of 101 men (19% of the cohort) in whom an MDE had supervened on a background of established DD.

204 men (38%) met the criteria for one or other (or both) disorders on enrolment. A further 56 appeared to have had a previous MDE, yielding a lifetime prevalence of 48% of men in the cohort who had ever had a depressive disorder.

HIV+ men did not differ in their prevalence of any of these disorders from HIV-/? and so, perhaps surprisingly, personal infection with HIV does not appear to be a significant determinant of depression in this group. Having HIV in one's community, of course, might well be involved.

The cross sectional prevalence of MDE in this sample (as measured by the Prime-MD) was more than eight times the annual prevalence of the condition (as measured by the Composite International Diagnostic Interview [CIDI]<sup>\*</sup>) in South Australian adult males in the NSMHW97 (3.6%).(Australian Bureau of Statistics, 1998)

<sup>&</sup>lt;sup>\*</sup> The comparability of these measures is discussed on page 294.



It should be remembered (as discussed on page 232) that men in the C&PP constitute a clinical cohort and so a higher prevalence would be expected in comparison with a community survey. It is of interest, however, that in on of the original validation studies for the Prime-MD, the prevalence of major depression was 6% in adult male attenders at four primary care clinics in the United States.(Linzer *et al.*, 1996) The prevalence seen in the C&PP cohort was five times this rate.

No general practice clinical prevalence studies appear to have been done using a diagnostic instrument<sup>\*</sup> to date in Australia but in a 1991 study, the prevalence (by DSM IIIR criteria) of Major Depression among hospital inpatients was 12%, or less than half the rate in the C&PP cohort.(Clarke *et al.*, 1991)

The prevalence of DD in the cohort was fourteen times the rate measured with the CIDI among South Australian adult men in NSMHW97 (1.9%).(Australian Bureau of Statistics, 1998)

<sup>&</sup>lt;sup>\*</sup> Although there have been several that have used screening or monitoring instruments such as the Beck Depression Inventory.

In a roughly contemporaneous study from a Canadian primary health care unit, the prevalence of DD in adult male attenders (as measured by the CIDI) was 3.9%.(Steiner *et al.*, 1999) The rate of DD (measured with Prime-MD) in the Programme cohort is almost seven times this rate.



The only head-to-head comparison in the literature between the CIDI and the Prime-MD (in its German version) was undertaken by Loerch and colleagues.(Loerch *et al.*, 2000) Their study suggests that the CIDI is *more* sensitive than the Prime-MD for both MDE and DD, and that the Prime-MD has an excellent negative predictive value for both conditions (that is, it is most unlikely to falsely diagnose a respondent positive). These characteristics would be expected to minimise, rather than magnify, the apparent differences in prevalence we have observed and so lend support to the conclusion that homosexually active men in the cohort were, indeed, much more likely to be seriously depressed or dysthymic than either men in the GIDI by other workers.

The social and historical correlates that may provide insight into the determinants of depressive disorders in the cohort are discussed on page 323 and behavioural correlates in the context of HIV transmission risk are discussed on page 359.

#### Zung depression rating scale

In addition to Prime-MD, the Zung Depression Rating Scale(Zung, 1965) was administered to participants who indicated either the presence of depressed feelings or reduced interest and pleasure in activities in their answers to the screening questions. The higher the score on this test, the greater the number and intensity of depressive symptoms reported.

For the purpose of the analysis an Effective Zung Score (EZS) has been calculated by employing the actual score for participants who answered a screening question affirmatively and completed the score, and allotting a score of 50 (the upper limit of normal for this test) to those who did not report the screening symptoms.

In keeping with the prevalence of depressive disorders, the ESZ did not differ significantly between HIV+ (mean: 50.6) and HIV-/? (mean: 50.6) men. Because the EZS was constructed *post hoc* for comparison with social factors in Part 3, no comparison groups were available for the measure. This analysis is presented on page 330.

#### Suicidal ideation

The Prime-MD depression questionnaire includes an inquiry about suicidal ideation in the prior two weeks.

26 of the 184 HIV+ participants (14%) answered this question affirmatively on enrolment, as did 60 (17%) of the 358 HIV-/? cohort members. These rates were not significantly different from each other.

A comparison for this rate is afforded by an Australian study undertaken by Jorm and colleagues in 1999–2001.(Jorm *et al.*, 2002) As part of this study the researchers administered a questionnaire to a population sample of 2332 male Canberra residents. Unpublished data provided by the lead author indicate that 2243 of the men identified as heterosexual. 232 of these men answered a question about having 'thought about taking your own life' *in the prior year* affirmatively, yielding a rate of 10%. (In the same sample, 18 of the 90 men whose sexual identity was other than heterosexual [20%] reported suicidal ideation in that time frame).

Although the difference in time frame complicates comparison of these data, it is of interest that cohort members were substantially more likely to report having thought about suicide *in the prior two weeks* than heterosexually-identified men in Jorm's study were to have had such thoughts in the prior year.



The social and historical correlates of suicidal ideation are considered on page 333. The rate of completed suicide in the cohort over time is discussed on page 316.

# Suicide attempt history

A history of suicide attempt is not sought in the Prime-MD instrument and as a consequence was not elicited from participants at enrolment into the C&PP. Because of the evidence emerging in the literature about the relationship between sexual orientation identity and suicide attempt risk, however, the question 'Have you ever tried to take your own life?' was added to the C&PP assessment when participants were reviewed for a second time, an average of 36 months after enrolment. (Other results from these later assessments are considered in Part 4.) At the time of data analysis, 210 men had completed Second Review. Of them, 52 (25%) reported having ever attempted suicide. This rate is comparable with most other studies of this topic among homosexually active or gay identified men in the literature, and substantially higher than that seen in general community samples of males (see page 171).

34 (65%) of the men who reported a suicide attempt in the cohort did so with an overdose of tablets, 8 (15%) by cutting the wrists or elsewhere on the body, 5 (10%) by a means related to driving, 2 (4%) by hanging or strangling, one by car exhaust fumes and two by 'other means'.

# Anxiety disorders

Prime-MD allows the diagnosis of Panic Disorder (PD) and Generalised Anxiety Disorder (GAD) according to the DSM-IV criteria. Unlike the two depressive disorders diagnosed, these conditions are mutually-exclusive by definition.

The responses of 56/542 men (10%) met the criteria for a diagnosis of PD on enrolment into the Programme. A further 47 (9%) met the criteria for GAD. Thus, a total of 103/542 participants (19%) had a diagnosable anxiety disorder at the time they enrolled.

There was no significant difference in the prevalence of these conditions when HIV+ and HIV-/? men were compared.

These cross-sectional rates are again much higher than the *annual* prevalence of these disorders identified among SA Males using the CIDI instrument in NSMHW97.(Australian Bureau of Statistics, 1998) In this community survey, the prevalence of PD was 0.9% (less than a tenth the prevalence detected by Prime-MD in the cohort) while for GAD it was 3.9% (less than half the rate in the cohort).

The social correlates of anxiety disorders in the cohort are considered on page 334, while their behavioural correlates in the context of HIV transmission risk are discussed on page 371.



# Recollection of childhood sexual abuse (CSA)

As with history of suicide attempt (see page 297) a question about a history of childhood sexual abuse (as defined by the respondent) was added to the Second Review assessment. 49 of the 210 homosexually active men who had undergone Second Review (23%) reported a recollection of sexual abuse before the age of eighteen.

26 men (12%) reported such an experience below the age of ten years and 31 men (15%) above the age of 10 (including 8 men [4%] who reported abuse in both age ranges). 15 men (7%) reported abuse by a family member and 43 (21%) by an outsider (including 9 men [4%] who reported both experiences).

These rates are substantially higher than those reported in a large (n = 876 males) general community sample of Australian men by Dunne in 2000, where the rate overall was 15.9%, and the rate among men aged 30–39 was 13.6%.(Dunne *et al.*, 2003) Comparison of the cohort rate with the rate for all men in this study using a 2x2 table identifies a statistically significant difference, with men in the cohort having an odds ratio of 1.62 (95%CI: 1.12 to 2.35; P = 0.0110 by FET) for reporting CSA.

It should be recognised that the Dunne study assessed CSA under 16 years while the C&PP question asked about under 18 years but the magnitude of the difference seems more than might be expected on this basis alone. Perhaps more importantly, however, as discussed, the cohort was recruited from men in general practice care who would be expected to be more likely to have health problems than men in a random telephone-based survey such as that undertaken by Dunne's group. Given the associations between CSA and health problems (see page 352) this sampling difference may have led to significant bias toward the selection of people who had experienced CSA in the cohort.

No association was seen between age and likelihood of reporting CSA in the cohort while in the Dunne study older men were more likely to report the experience.

#### Substance use

#### Tobacco

362 of the 542 participants (67%) had ever smoked tobacco and 237 (44%) were current smokers at the time of enrolment.

HIV+ men were significantly more likely both to have ever smoked (75% cf 63%, OR = 1.80; 95%CI: 1.21 to 2.67; P = 0.0038 by FET) and to have been current smokers at the time of enrolment (58% cf 36%; OR = 2.44; 95%CI: 1.69 to 3.51 P<0.0001 by FET) than HIV-/? men.

The rate of current smoking in HIV+ participants was twice that of Australian males in general (29% in the NDSHS98).(Higgins *et al.*, 2000) It is comparable with, if a little higher than, the rate of 54.5% in (HIV+) respondents to the Futures II survey.(Grierson *et al.*, 2000)

Some specific comparators are available for this characteristic with other Australian general practice attenders. Among the 12,230 Australian men attending GPs in the BEACH study, (Bayram *et al.*, 2003) 28.8% were current smokers, a rate very similar to that seen in the population in NDSHS98 (and substantially lower than the rates in the cohort).

The Public Health Division of the New South Wales Health Department, on the other hand, conducted a random sample of residents of NSW over age 16 in 1997 and 1998.(Public Health Division, 2000) The sample included, among other characteristics, current smoking status and whether the respondent had seen a GP in the prior twelve months. In this study, people who had seen a GP were *less* likely to be current smokers (23%) than people who hadn't (28%). These two reports suggest that recruitment through general practice, as in the current study, would be expected to yield a sample with a similar, or if anything, *lower* rate of smoking than a general population survey. Thus, the high rate of smoking seen in the C&PP cohort may represent a minimum estimate of the true rate in the population from which it was drawn. The degree of health inequality between homosexually active men and other men in the South Australian community, with regard to current smoking, may be even greater than estimated above.

The correlates of tobacco use are considered on page 335 and the scales used to rate level of use of tobacco and other substances in the cohort are shown in Appendix 2 on page 477.



#### Alcohol

527/542 participants (97%) had ever used alcohol and 480 (89%) were current drinkers on enrolment. These rates are somewhat higher than the 93% and 84%, respectively, reported by Australian males in the NDSHS98.(Higgins *et al.*, 2000) 104 men (19%) reported consuming more than four standard drinks a day at least occasionally. These proportions did not differ significantly between HIV+ and HIV-/? participants. Among men attending GPs in the BEACH study, 78.3% were current drinkers.(Bayram *et al.*, 2003) This suggests that sampling through GP attendance might (as with smoking) generally yield a lower rate than community surveys. This would tend to minimise (falsely) the apparent health inequality with regard to alcohol use experienced by homosexually active men.

The rate of current drinking in the cohort was somewhat higher than the 82.3% seen (among HIV+ people) in the Futures II study but slightly different question structure could account for this.(Grierson *et al.*, 2000) Futures II did not measure the amount or frequency of alcohol consumed.

The Prime-MD allows for the identification of the likelihood of an alcohol use disorder according to the DSM-IV criteria. The presence of an alcohol disorder was diagnosed as likely with this tool in 116 men (21% of the cohort). This is more than twice the rate of alcohol use disorder diagnosed by the CIDI in SA males in the NSMHW97(7.5%).(Higgins *et al.*, 2000)



The social correlates of alcohol use are discussed on page 336 and its relationship with sexual behaviour considered on page 369.

#### Cannabis

335/542 participants (62%) had ever used cannabis, 239 (44%) had used in the last year, and 124 (22%) were using at least once a week at the time of enrolment.

HIV+ men were significantly more likely to have used at each level of consumption than HIV-/? men, as shown in Table 6:

Cannabis usage	HIV+	HIV-/?	OR	95%CI	P (by FET)
Ever used	73%	56%	2.09	1.42 to 3.08	0.0002
Used in last year	63%	32%	3.62	2.52 to 5.20	< 0.0001
At least 1x/week	33%	15%	2.72	1.79 to 4.16	< 0.0001

Table 6: Cannabis use levels by HIV status

Even the rates for HIV-/? men, however, are substantially greater than those for Australian men in the NDSHS98 (44% ever used and 21% used in the last year).(Higgins *et al.*, 2000)

The rate of cannabis use in the last year in HIV+ men (63%) was not significantly different from the rate of 56% reported in the Futures II report.

The social correlates of cannabis use are considered on page 337 and its relationship with sexual behaviour is discussed on page 369.



#### Nitrites

272/542 participants (50%) had ever used inhaled nitrites ('poppers' or 'amyl'), 147 (27%) had used in the last year but only 13 (2%) were using the drug at least once a week on enrolment.

HIV+ men were significantly more likely to have ever used nitrites (68% vs 41%: OR = 3.15; 95%CI: 2.17 to 4.59; P < 0.0001 by FET) and to have used them in the last year (38% vs 22%; OR = 2.15; 95%CI: 1.46 to 3.18; P = 0.0001 by FET). There was no significant difference on the basis of HIV status among the small number of participants who reported frequent nitrite use.

Even the somewhat lower rates of use by HIV-/? men were markedly greater than those for Australian men in the NDSHS98 (5% ever used, 1% used in last year).(Higgins *et al.*, 2000) The use by HIV+ men in the prior year was not significantly different from the rate of 39% reported by respondents in the Futures II study.

The social correlates of nitrite use are considered on page 337, and its relationship with sexual behaviour is discussed on page 369.



#### Amphetamines

153/542 C&PP participants (28%) had ever used amphetamines ('speed'), 66 (12%) had used in the year before enrolment, but only 4 (1%) were using the drug at least once a week at the time they enrolled.

HIV+ men were more likely to have ever used (37% cf 24%; OR = 1.88; 95%CI: 1.28 to 2.77; P = 0.0017 by FET) but the difference in their frequency of recent use (15% cf 11%) was not significant.

Even the lower rates of amphetamine use by HIV-/? homosexually active men in the cohort are more than twice those seen among Australian males generally in the NDSHS98 (11% ever used, 5% used in last year).(Higgins *et al.*, 2000)

The social correlates of amphetamine use are considered on page 337, and its



relationship with sexual behaviour is discussed on page 369.

#### Lysergic acid diethylamide (LSD)

139/542 enrolees (27%) had ever taken LSD or related agents ('trips') but only 26 (5%) had used them in the year prior to enrolment. HIV positive men were significantly more likely to have ever taken trips (34% cf 22%; OR = 1.86; 95%CI: 1.25 to 2.76; P = 0.0026 by FET) but no more likely to have used them recently.

The rate of ever having used these drugs in the cohort was substantially higher than that identified for Australian males in the general community in the NDSHS98 (13%) but the rate of recent use was of the same order (4% among males in the NDSHS98).(Higgins *et al.*, 2000)

The social correlates of LSD use are considered on page 338.



#### Ecstasy (methylenedioxymethamphetamine/MDMA)

146 of the 542 homosexually active men enrolled in the Programme (27%) reported ever having used ecstasy and 52 (10%) had taken the drug in the twelve months before enrolment. Only two participants (both HIV+) were using more often than 'occasionally' when they joined the C&PP.

HIV+ cohort members were significantly more likely to have ever used ecstasy (34% cf 23%; OR = 1.66; 95%CI: 1.12 to 2.45; P = 0.0140 by FET) but any difference in the number who had used in the prior year was not statistically significant (8% for positive men, 10% for negative). All of these rates are substantially higher than the rates for Australian males in the NDSHS98 (6% ever used, 3% in last year).(Higgins *et al.*, 2000)

The social correlates of ecstasy use are considered on page 338, and its relationship with sexual behaviour is discussed on page 369.



#### Heroin

58/542 participants (11%) reported ever having used heroin. 10 men (2%) had used in the year prior to enrolment and three were using more often than 'occasionally' when they joined the Programme.

The rate of prior use is substantially higher than the NDSHS98 figure for males (3%) but the rate of recent use appears to be of the same order as the general community (1%).(Higgins *et al.*, 2000)

No significant difference in the past or present use of this drug was seen comparing HIV+ with HIV-/? men.

The social correlates of heroin use are considered on page 339.

#### Injecting use of any illicit drug

87/542 enrolles (16%) reported ever having injected drugs and 25 (5%) had injected in the last year. These rates are substantially higher than the rates of 2.8% and 1% respectively among males in the NDSHS98.(Higgins *et al.*, 2000) It is believed that the discrepancy in the rates of recent injection and recent heroin use relates to the injection of amphetamines being much more common among homosexually active men than men generally.

HIV+ men were more likely to have ever injected (22% cf 13%; OR = 1.85; 95%CI: 1.16 to 2.94; P = 0.0130 by FET) than HIV-/? men, and the difference in likelihood of recent injecting use approached statistical significance (7% vs 3%; OR = 2.19; 95%CI: 0.979 to 4.91; P = 0.0810 by FET).

The social correlates of injecting drug use are considered on page 339.

# Function and quality of life (short form 36)

The short form 36 (sf36) questionnaire subjectively assesses function and quality of life across eight domains.(Ware, 1993) Each domain is scored out of a possible 100 and a higher score indicates a higher level of function and quality of life. The two 'Role' domains assess the extent to which physical and emotional health (respectively) are felt to impair the respondents ability to fulfil their social responsibilities. Mean scores for HIV+ and HIV-/? men at enrolment are compared in the table below:

sf36 domain	HIV+	HIV-/?	P value*
Physical Function	81.6	85.8	0.0174
Role Physical	68.2	75.1	NS
General Health	70.6	72.9	NS
Bodily Pain	60.1	60.7	NS
Vitality	43.6	43.8	NS
Social Function	65.7	64.2	NS
Role Emotional	61.6	61.5	NS
Mental Health	56.7	54.6	NS

Table 7: Mean sf36 scores at enrolment (n = 517)

\* By t-test with Welch's Correction (ttWC)

It can be seen that the self-ratings of HIV+ and HIV-/? men were remarkably similar. The only significant difference between the groups was in the Physical Function domain where HIV-/? men, on average, reported slightly better functioning.

The mean scores for the whole cohort are compared below with the published norms for these measures for males in the SA population (n = 1480).(Behavioural Epidemiology Unit, 1995) The statistical significance of the differences has been calculated from the mean, standard deviation and number of values provided in the norms document using the ttWC to derive the P values in Table 8 on page 310.

sf36 domain	C&PP cohort	SA males	P by ttWC
Physical Function	84.4	88.6	<0.0001
Role Physical	72.8	82.6	< 0.0001
General Health	72.1	74.3	0.0152
Bodily Pain	60.5	79.9	<0.0001
Vitality	43.7	68.0	<0.0001
Social Function	64.7	90.6	<0.0001
Role Emotional	61.5	90.3	<0.0001
Mental Health	55.4	81.3	<0.0001

Table 8: Mean sf36 scores compared with SA population norms for males(Behavioural Epidemiology Unit, 1995)

It is clear that, on average men, in the cohort self-assessed all aspects of their health on enrolment below the level of men in the South Australian community generally.

To exclude differences in age distribution as a confounding factor, a further set of comparisons was done including only men in the 35-44 age range from the population study (n = 301). In six of the domains the magnitude of difference between the cohort and the general population was *greater* in this comparison, and for the remaining three (Vitality, Social Function and Role Emotional) it was a little smaller but still had P for difference of <0.0001.

To assess for any likely effect from clinical recruitment, the mean values for men in the cohort were compared with those obtained from the 227 men attending for general practice care in the WHDS.(Griffith *et al.*, 2001) Insufficient data were provided in the report of this study for statistical comparison to be undertaken but the values are plotted graphically as the grey line with circular markers on the chart below. It shows results at the 'mental' end of the scale that appear to be about mid way between those for men in the C&PP and the South Australian population norms. At the (right hand) 'physical' end of the sf36 spectrum, the values for WHDS respondents are lower than those for men in the cohort but it must be remembered that the WHDS group is substantially older.

The sf36 curves for males and females in the WHDS were almost identical, and so the profile for all WHDS participants in the 30-49 age group (which includes the mean age of the C&PP cohort) has also been plotted as the broken black line with open square markers.<sup>\*</sup> It can be seen that, visually at least, the profile of the C&PP cohort follows the curve for middle-aged participants in the WHDS very closely on the left end of the sf36 spectrum (pertaining to physical health) but diverges appreciably at the right hand end indicating substantial psychosocial health inequality.



Finally, a comparison was made with the one peer-reviewed study of the sf36 in a general practice sample, reported in 1998 by Lin and Ward.(Lin *et al.*, 1998)

<sup>&</sup>lt;sup>\*</sup> Age specific profiles were not broken down by sex in the WHDS report.

The sample in this study was 64 patients (41 women and 23 men)<sup>\*</sup> who attended for general practice care in metropolitan Sydney. Participants were recruited in the practice waiting room but the sf36 was not administered at recruitment. Rather it was posted to them for completion on two occasions, a week and two weeks after the GP consultation. According to the authors:

[t]he interval of one week was chosen to allow time for resolution of an acute health condition prompting the original attendance in general practice. The interval of another week between the two questionnaires was determined on the basis that participants health would remain stable enough in this short term, but would not allow recall and replication of their previous answers.(Lin *et al.*, 1998, p S95)

In this study, means and standard deviations for each sf36 scale were provided, allowing *post hoc* statistical comparison with the C&PP cohort as documented in Table 9.

sf36 Domain	C&PP cohort	Lin & Ward 1 week post- consult	Lin & Ward 2 weeks post- consult	P C&PP vs Lin 1 wk by ttWC	P C&PP vs Lin 2 wk by ttWC
Physical Function	84.4	80.2	85.0	NS	NS
Role Physical	72.8	83.9	76.9	0.0109	NS
General Health	72.1	70.7	70.2	NS	NS
Bodily Pain	60.5	70.2	72.6	0.0028	0.0003
Vitality	43.7	61.2	62.4	< 0.0001	< 0.0001
Social Function	64.7	80.8	80.1	< 0.0001	< 0.0001
Role Emotional	61.5	83.9	76.9	< 0.0001	0.0031
Mental Health	55.4	71.7	72.2	< 0.0001	< 0.0001

Table 9: Comparison of mean sf36 scores, C&PP vs Lin & Ward (Lin et al., 1998)

These values have been plotted in the chart below and a similar pattern to that seen in the comparison with middle aged people in the WHDS is evident, this time with *post hoc* statistical validation of the visible differences.

<sup>&</sup>lt;sup>\*</sup> Since the profiles for males and females were almost identical in the WHDS it is hoped that the gender content of Lin and Ward's sample will not hinder valid comparison with men in the C&PP, but this remains a concern.

The results of statistical comparison with Lin & Ward's study and visual comparison with data from the WHDS confirm that, although clinical samples can be expected to show impaired sf36 profiles compared with population norms, significant health inequality still appears to exist between men in the C&PP cohort and other general practice recruited samples of Australians with regard to health characteristics measured by the Bodily Pain, Vitality, Social Function, Role Emotional and Mental Health scales of the sf36.



#### Mortality

The rate of death in a population has generally been regarded, for obvious reasons, as among the most important indicators of its health status. Since the Care and Prevention Programme cohort has been followed longitudinally, the mortality rate among the group can be calculated and compared with the rate in comparison populations.

Sixteen of the 542 men who enrolled in the C&PP (3%) had died to June 30<sup>th</sup>, 2003. The most likely causes of their deaths are documented in Figure 44.



Figure 44: Likely cause of death in cohort members.

To obtain death rates, the population at risk (participants with whom the Programme team was still in touch – including people who had died) in each age range was calculated based on age at the midpoint of follow up (1385 days = 3.76 years). The number of deaths in each age range over the follow up period was compared with the predicted number of deaths among males in each age range in the SA population (assuming a constant death rate for that period<sup>\*</sup>) based on 2001 demographic information from the Australian Bureau of Statistics. (Australian Bureau of Statistics, 2002b) These comparisons are shown in Table 10 on page 315.

Based on these figures, the Standardised Mortality Ratio (SMR) (using the indirect standardisation method)(Pan American Health Organization, 2002) is calculated by dividing the observed deaths in the 3.79 years of follow up (16) by the predicted number from the SA population derived in Table 10 (5.34) to yield a SMR of 3.00.

<sup>&</sup>lt;sup>\*</sup> And examination of the death trends suggests that this is very reasonable.

The standard error (SE) for the SMR is calculated by the following formula:(Pan American Health Organization, 2002)

SE = 
$$\frac{SMR}{\sqrt{observed deaths}}$$
 =  $\frac{3.00}{4}$  = 0.750

The 95% confidence intervals are then derived as SMR +/- (1.96 x SE). Thus the SMR for men in the C&PP is 3.00 (95%CI: 1.53-4.46) and the conclusion can be drawn that men in the cohort had an age standardised death rate that was significantly greater than men in the SA population in 2001.

Age C&		C8.DD	Obconvod	Deaths	SA Male	Age Specific	Predicted Deaths in
	Population	Deaths	SA Males	Population	Death Rate	C&PP in 3.79 years	
		Population	Deaths	2001	2001	SA Males	follow up
	15-19	3	0	26	53,192	0.000489	0.00556
	20-24	11	0	48	49,020	0.000979	0.0408
	25-29	30	0	52	50,848	0.00102	0.116
	30-34	54	1	75	55,175	0.00136	0.278
	35-39	79	4	101	57,133	0.00177	0.530
	40-44	76	3	97	57,796	0.00168	0.484
	45-49	66	2	131	53,556	0.00245	0.612
	50-54	55	1	183	52,324	0.00350	0.729
	55-59	26	4	272	40,836	0.00666	0.657
	60-64	23	1	337	33,156	0.0102	0.886
	65-69	9	0	435	28,067	0.0155	0.529
	70-74	4	0	847	27,100	0.0313	0.474
	TOTAL	436	16	2604	558,203	0.00466	5.34

Table 10: Observed and expected deaths by age in C&PP cohort, based on SA population data. (Australian Bureau of Statistics, 2002b)

The issue relating to the 'clinical' recruitment of the C&PP for comparison with population data (see page 232) arises for this outcome as it does for the others. No Australian data on mortality among primary care populations could be identified. Limited information was available for the United Kingdom, where an interest in mortality in general practice care seems to have been taken after the notorious Shipman murders in the 1990s. Beaumont and Hurwitz, for example, in 2003, reported the deaths over three years in a single large British practice.(Beaumont *et al.*, 2003) 76% of deaths in this study, however, occurred in people aged over 65 years and, since only 10 men in the C&PP cohort (1.84%) were in this age range, comparison would be inappropriate. No age-specific death rates were reported in the study.

Ultimately, no appropriate clinical cohort comparators were identified and this should be borne in mind in interpretation of the results. It should be remembered, however, that C&PP recruitment was dependent only on GP attendance and a high proportion of Australians attend general practice in any year, let alone in the five years for which the Programme had been recruiting at the time of analysis. Thus it would be most surprising if the very substantial difference in death rates were wholly an artefact of 'clinical' recruitment.

The high death rate (in comparison with population studies) described above was seen in spite of the health benefits documented in association with participation in the Programme and discussed in Part 4. This suggests that the cohort is drawn from a population with a markedly higher mortality than the general South Australian community.

## Completed suicide

Using the same methodology described above for Standardised Mortality Ratios, specific SMRs for suicide were calculated based on numbers in Table 11. Age specific suicide death rates are not provided on a state by state basis by the Australian Bureau of Statistics and so the Australia-wide age specific rates were used to calculate the expected deaths for the calculations.(Australian Bureau of Statistics, 2002c) Note that wider age strata are used by the ABS for this rarer outcome, and the same groupings have been used in this calculation.

Age	C&PP Population	Observed Deaths	Age-specific Suicide Death Rate Australian Males 2001 (per 100,000)	Predicted Deaths in C&PP in 3.79 years follow up
15-24	14	0	20.3	0.0108
25-34	84	0	33.9	0.108
35-44	155	3	30.2	0.177
45-54	121	3	23.3	0.107
55-64	49	0	18.9	0.0351
65-74	13	0	19.9	0.00981
TOTAL	436	6	-	0.448

Table 11: Observed and expected suicide deaths by age in C&PP cohort based on Australian population data. (Australian Bureau of Statistics, 2002c)

Using the formulae described on page 315, the suicide specific SMR for men in the C&PP can be calculated to be 13.4 with a standard error of 5.47 and 95% confidence limits of 2.68 - 24.1. Thus it can be concluded that men in the cohort had a suicide specific standardised death rate that was very significantly higher than men in the Australian population in 2001.

As with the mortality data, no appropriate clinical recruitment comparison groups could be identified and the comments above about this issue should be borne in mind in interpretation of the data.

The high levels of completed suicide were seen despite the dramatic and measurable fall in rates of suicidal ideation in association with participation in the Programme (see page 400) and suggest a very high rate among the population from which the cohort was recruited.

#### Discussion

Important methodological issues were faced when attempting to determine the extent of health inequality affecting homosexually active men in South Australia. While the health status of men who enrolled in the C&PP cohort has been characterised in detail, the Programme's history of having been established and funded as a service provision endeavour, rather than expressly as a research project, means that no control group was available for direct comparison.

There exists, however, a wealth of data on the health characteristics of Australian men generally, and to a lesser extent on Australian men sorted on the basis of sexual orientation identity or sexual behaviour, from a variety of sources. Comparison with other data sources can be valid but requires careful consideration of the potential for bias resulting from factors including the method of sampling and the instruments used. These issues have been discussed and allowed for in this chapter, but the conclusions should still be treated with caution.

The health characteristics of participants in the C&PP and the comparisons drawn in this chapter, subject to the various limitations discussed, together with other available data, support the conclusion that homosexually active South Australian men are subject to health inequality relative to men in the general community.

Specific conclusions about the dimensions of this inequality with regard to health and health related characteristics are summarised in Table 12. They are drawn from comparisons between C&PP participants and other groups supported by other health data on Australian men analysed by sexual orientation identity or sexual behaviour discussed in the chapter. Particular issues in the comparisons and the degree of support for the conclusion are mentioned in the 'notes' column.

It is also of interest that for a small number of health and health-related characteristics, homosexually active men may experience inequity in the other direction, that is they may be somewhat advantaged. Body mass index, is an example, where 49% of HIV-/? men in the cohort had a BMI in the overweight or obese range compared with 59% of men attending GPs in the BEACH cohort.(Bayram *et al.*, 2003)<sup>\*</sup> The proportion of men with one or more university degrees is another. These characteristics, though few, underline the cultural and societal distinctness of the populations of homosexually active and non-homosexually active Australian men and support the application of population health approaches such as a health inequity framework in consideration of their health status.

In Part 3, the social and historical correlates of some of these health characteristics will be examined in an attempt to ascertain whether any elements of this health inequality may be examples of health *inequity* as defined by Whitehead (see page 39).

<sup>&</sup>lt;sup>\*</sup>HIV+ men in the cohort had an even lower proportion but this may have been related to pathological weight loss on the basis of their HIV or its treatment.

Health or health-	Approximate inequality	Notes
Mortality	SMR = 3.00	
Completed suicide	Specific SMR = 13.4	
HIV infection prevalence	30 fold	Clear evidence from multiple sources.
Lifetime syphilis history	3 – 4 fold	Evidence from two comparison sources.
Anogenital herpes	2 – 7 fold	Part of difference may be due to HIV increasing clinical
history		expression of HSV infection.
Anogenital warts	6 fold (even for HIV-/? homosexually	Much greater for HIV+ men but same effect as for herpes
history	active men)	may be in play. Evidence from two comparisons.
Gonorrhoea history	9 – 14 fold	Good evidence from multiple comparisons.
Chlamydia history	> 3 fold	
Any STI history	4 fold	
Current major	5 – 8 fold	Good evidence from clinical comparisons
depression	• • • • • • • • • • • • • • • • • • • •	
Current dysthymia	7 – 14 fold	Good evidence from clinical comparisons
Recent suicidal	1.5 – 2 fold	
ideation		
Suicide attempt history	3 – 4 fold	#
Current panic disorder	10 fold	#
Current generalised	2 fold	#
anxiety disorder		
Lives alone	>2 fold	#
Not employed	1.3 fold	Compared with WHDS GP sample.
Median income	Marked for HIV+ men	Compared with WHDS GP sample and census
	Definite for HIV-/? men	••••••••••••••••••••••••••••••••••••••
Sexually active with	9 fold	But, homosexually active men who have casual sex are
casual partners	(6 fold if oral sex excluded)	half as likely to have casual anal sex without a condom
		than men with casual neterosexual parmers are to have
Descript of shildhood	A A £_1_1	nad casual vaginal sex without a condom.
Report of Childhood	~1.4 tola	
	2 fold among UIV/1 man	Page 290.
Current lobacco use	1.2 = 1.5 fold among HIV-/?	
Current alcohol use		   #
Likoly ourrent alcohol	2 faid	# #
Likely current aconor	2 1010	#
Recent cannabis use	2 fold	<i>₩</i>
Recent nitrite use	> 20 fold	μ μ
Recent amphetamine	2 fold	μ μ
	21010	π
Ever used LSD	2 fold	
Recent erstasy use	2 fold	μ μ
Ever used heroin	3 fold	μ <i>π μ μ μ</i>
Ever injected illicit	5 fold	#
drug	5 1010	#
Recently injected illicit	5 fold	
drun	5 1014	π
Mid arm muscle	C&PP participants 90% of US	
circumference	population norm	π
Peak Expiratory Flow	Participants mean PEER <80% of	# Probably related as least in part, to higher smoking rate
Rate	norms	
sf36	Significantly poorer self rated health	Good evidence from comparison with two other Australian
0100	on Bodily Pain. Vitality, Social	primary care samples
	Function. Role Emotional and	p
	Mental Health scores	

 Table 12: Dimensions of health inequality experienced by homosexually active men

 (#: Comparison between C&PP and population samples only – should be interpreted with this in mind)

# PART THREE Correlates & **Consequences:** Was the health inequality also health inequity, and how was this related to HIV transmission behaviours?

# Chapter 7: Social and Historical Correlates

# Introduction

Part 2 of the thesis established that homosexually active South Australian men appear to differ, on average, from other men on the basis of a range of health and health related characteristics. That is, they are subject to health inequality.

In Part 3, the expression of some of these characteristics among men in the cohort will be compared with a variety of social and historical factors. The purpose of this analysis is to determine whether any of the health inequalities already described may be related to conditions that may be considered unjust or unfair. If this were found to be the case, it could be argued that the health inequality under discussion also represents *health inequity* as defined by Whitehead (see page 39).

The majority of health characteristics will be considered in this chapter and the particular case of sexual behaviour in the context of HIV transmission will be discussed in Chapter 8. Reference will be made to how this very important determinant of the health of homosexually active men in South Australia is influenced by complex interactions between social conditions and health characteristics, some of which are, in turn, socially produced.

It is recognised that all that can be shown in this analysis is *association* between health characteristics and possibly unfair conditions. This cannot be assumed necessarily to imply causality and certainly cannot be taken to confirm a direct cause and effect relationship between the two. What the analysis can provide, however, is support for a multi-level model of the kind advocated by Krieger (see page 43) that integrates 'social and biological reasoning and history' to make sense of the likely health effects of the social oppression experienced by homosexually active people in Twenty-first Century Australia.(Krieger, 2001a 671)

Standard general sociodemographic data were collected from C&PP participants at enrolment. These data were used to identify the social correlates of a range of health characteristics that are reported in this chapter.

For these analyses, the following health characteristics at enrolment were assessed (as dependent variables) for their social correlates:

- Lifetime syphilis history (dichotomous variable, yes/no)
- Lifetime anogenital herpes history (dichotomous variable, yes/no)
- Lifetime anogenital warts history (dichotomous variable, yes/no)
- Lifetime gonorrhoea history (dichotomous variable, yes/no)
- Lifetime chlamydia history (dichotomous variable, yes/no)
- Lifetime NSU history (dichotomous variable, yes/no)
- Current Major Depressive Episode (dichotomous variable, yes/no)
- Current Dysthymic Disorder (dichotomous variable, yes/no)
- Either current depressive disorder (dichotomous variable, yes/no)
- Effective Zung Score (interval variable, see page 330)
- Recent suicidal ideation (dichotomous variable, yes/no)
- Current Panic Disorder (dichotomous variable, yes/no)
- Current Generalised Anxiety Disorder (dichotomous variable, yes/no)
- Tobacco use level (ordinal variable, see Appx 2 on page 477 for scale)
- Alcohol use level (ordinal variable, see Appx 2 on page 477 for scale<sup>\*</sup>)
- Cannabis use level (ordinal variable, see Appx 2 on page 477 for scale)
- Nitrite use level (ordinal variable, as for Cannabis)
- Amphetamine use level (ordinal variable, as for Cannabis)
- LSD use level (ordinal variable, as for Cannabis)
- Ecstasy use level (ordinal variable, as for Cannabis)
- Heroin use level (ordinal variable, as for Cannabis)
- Injecting drug use level (ordinal variable, see Appx 2 on page 477 for scale)
- sf36 domain scores (interval variable, see page 309 for description)

These characteristics were chosen because of the evidence for health inequality regarding them outlined in Chapter 6 and because data had been collected from the whole C&PP.

<sup>&</sup>lt;sup>\*</sup> Alcohol use was re-coded from the original nominal grid to give an ordinal scale as described in Appendix 2.
The health outcomes that might be thought the most important, namely mortality and completed suicide, were (fortunately) relatively infrequent events and so meaningful assessment for associations could not be undertaken for them.

The following social attributes at enrolment were compared (as independent variables) with the health characteristics above:

- Age (as an interval variable)
- Employment status (as a dichotomous variable constructed from the nominal employment question using the definition of 'employed' on page 250)
- Income group (as an ordinal variable according to the scale in Appendix 1 (see page 473)
- Educational attainment level (as an ordinal variable according to the scale in Appendix 1 (see page 473)
- Occupation type (as an ordinal variable according to the scale in Appendix 1 (see page 473)<sup>\*</sup>
- Living alone (as a dichotomous variable constructed from the nominal living arrangements variable by separating 'live alone' from all other answers)

In addition to these analyses, to investigate the relationship between psychological disorders and substance use, separate calculations were undertaken using the presence or absence of MDE, DD, PD, and GAD as dependent dichotomous variables and comparing them with levels of use of the various substances listed as independent variables.

Thus the levels of substance use appear as dependent variables in analyses to determine their social correlates (and perhaps precursors) and as independent variables in analyses to explore whether they contribute to the production of some psychological health outcomes. This duality reflects the complex and contested position that substance use occupies in the social production of health. Substance use is sometimes viewed as a health outcome (in discourses like 'alcoholism' 'intoxication' or 'drug dependency') and sometimes as a health determinant (in discourses like 'smoking causing cancer' and 'pot smoking leading to depression').

<sup>\*</sup> Though it is recognised that consideration of occupation type along an ordinal, class-like, scale is problematic – see discussion of social class on page 33

It should be remembered that a correlation between the level use of a drug and a health outcome such as a depressive condition may result from a variety of mechanisms. These would include the drug causing the depressive state or symptoms indistinguishable from it, the depressive condition leading to increased drug consumption, the two factors being related through a third (unmeasured) variable or a combination of these effects.

Multi-level models of health production such as those discussed on page 47 allow for such complexities and dualities to be considered.

It should also be borne in mind that the use levels of many of the listed substances are correlated with the use of others in the list as indicated by the correlation matrix in Table 13. These associations lead to an absence of 'independent' association for many of the substance variables in multivariate analysis, even when univariate associations are seen.

	Tabaaaa	Aleshel	Canaahia	N Literite	America		<b>F</b> astası.	Llausia	المراجع والأنواح
	TODACCO	AICOTIO	Cannabis	Nitrite	Amphetamine	LSD	Ecsiasy	Heroin	Injecting
	Use	Use	Use	Use	Use	Use	Use	Use	Drug Use
Tobacco		0.0770	0.395	0.0742	0.272	0.193	0.227	0.179	0.250
Use									
Alcohol	0.0770		0.0052	0.0775	0.141	0.0615	0.115	0.0040	0.0190
Use									
Cannabis	0.395	0.0052		0.250	0.342	0.387	0.343	0.141	0.296
Use									
Nitrite	0.0742	0.0775	0.250		0.141	0.0979	0.216	0.0275	0.035
Use									
Amphetamine	0.272	0.141	0.342	0.141		0.510	0.588	0.253	0.539
Use									
LSD	0.193	0.0615	0.387	0.0979	0.510		0.514	0.272	0.413
Use									
Ecstasy	0.227	0.115	0.343	0.216	0.588	0.514		0.245	0.361
Use									
Heroin	0.179	0.0040	0.141	0.0275	0.253	0.272	0.245		0.639
Use									
Injecting	0.250	0.0190	0.296	0.0351	0.540	0.413	0.361	0.639	
Drug Use									

Table 13: Correlation matrix for relationships between reported substance use levels at enrolment. Spearman correlation coefficients rounded to three significant figures. All correlations are positive. Shaded cells indicate correlations stronger than 0.200.

The statistical methods employed for these comparisons are listed in Table 14 according to the data characteristics of the variables involved. All analyses were undertaken utilising the InStat programme,(GraphPad Software, 1998) except logistic regression for which EpiInfo was used.(Centers for Disease Control and Prevention, 2005)

Hoalth		Social correlat	variable[s]) analy	ysis and data form			
characteristic (dependent variable) data form		Univariate	Multivariate analyses				
	Dichotomous (eg HIV+ vs HIV-/?)	Nominal (eg employment status)	Ordinal (eg income group)	Interval (eg age)	Dichoto- mous	Ordinal	Interval
Dichotomous (eg presence or absence of MDE)	2x2 table, odds ratio and Fisher's Exact Test	Dichotomised (eg employed vs not) then as for dichotomous	Comparison of medians for variable by Mann-Whitney Test	Comparison of means for variable by t- test (or, if not normally distributed, as for ordinal)	Logistic regression	Logistic regress- ion	Logistic regress- ion
Ordinal (eg frequency/ recency of cannabis use – see scale in Appendix 2 on page 477)	Comparison of medians for characteristic by Mann- Whitney Test	Dichotomised (eg employed vs not) then as for dichotomous	Spearman's correlation	Spearman's correlation	Multiple linear regression (dummy variable)	Multiple linear regress- ion	Multiple linear regress- ion
Interval (eg sf36 Physical Function Score)	Comparison of means for characteristic by t-test (or, if not normally distributed, as for ordinal)	Dichotomised (eg employed vs not) then as for dichotomous	Spearman's correlation	Pearson's correlation (or if not normally distributed as for ordinal)	Multiple linear regression (dummy variable)	Multiple linear regress- ion	Multiple linear regress- ion

Table 14: Statistical methods used according to data forms

It can be seen that a large number of comparisons have been made. All of the listed comparisons have been undertaken and all results that showed a significant (P< 0.0500) P value have been reported. For brevity, 'non-significant' results have not been presented.

Multiple comparisons increase the likelihood that at least one chance association will be falsely concluded to be significant – a so-called 'type I error'. While there is controversy about the importance of this problem in epidemiological research,(Perneger, 1998; Rothman, 1990) (see page 353) some authorities recommend that P values should be adjusted to account for this effect.(Curtin *et al.*, 1998)

The Bonferroni Adjustment provides a simple but conservative technique for calculating a more stringent P value in this setting to compensate for the increased likelihood of a type I error in multiple comparisons.(Curtin *et al.*, 1998) In this method the P value chosen to indicate significance is simply divided by the number of comparisons drawn in the analysis. For each of the health outcomes listed above (page 324), six comparisons have been made with social correlates. On this basis, the Bonferroni Adjustment would require that a P value of 0.05/6 = 0.0083 should be used to test significance at a level comparable to the 0.05 level for a single comparison. Many of the associations identified have 'raw' P values of <0.0083, but some do not and this should be borne in mind when the meaning of the associations discussed is considered.

In addition to the univariate analysis for associations between health characteristics and social variables, multivariate analyses were undertaken comparing each health outcome with the all of the social variables acting together. Since the study was seeking to explore the complexity of the production of the health outcomes, all of the social variables were included in the initial multivariate models. The bivariable selection (BVS) method for choosing which variables to include in a multivariate model was specifically not used. Despite the popularity of this method (whereby only variables that show significant univariate associations with the outcome are included in multivariate models) in biomedical research, Sun and colleagues were strongly critical of the technique. They pointed out that:

[a]lthough it seems logical to infer that a nonsignificant risk factor in bivariable analysis is likely to remain nonsignificant in multivariable analysis, there are exceptions. If risk factors ("independent variables") are not truly independent of each other,<sup>\*</sup> a nonsignificant risk factor in bivariable analysis is not necessarily nonsignificant in multivariable analysis.(Sun *et al.*, 1996 907)

They provided hypothetical and real world examples of such scenarios, and argued that the us of 'the BVS method of selecting variables for multivariable analysis is inappropriate and may produce inaccurate determinations of the contributions of independent variables to the outcome'.(Sun *et al.*, 1996 907) Examples of this phenomenon, have indeed appeared in the data (see correlates of amphetamines use on page 337), which supports the decision to use full models for this investigation.

 $<sup>^{*}</sup>$  As would be expected to be the case for the social variables in the present analysis. 328

In addition to the whole model multivariate analyses, for some health characteristics, additional models were constructed with fewer variables to explore particular relationships, as described in the text.

## Correlates of sexually transmitted diseases history

The associations identified between a lifetime history of each of the sexually transmitted diseases and the social variables (calculated according to the statistical methods described in Table 14) are shown in Table 15. As can be seen, older age was associated with a history of several of the STIs but few other associations were seen.

Health characteristic	Association type	(older) Age	Not being employed	(lower) Income group	(lower) Educational attainment	('lower') Occupation type	Living alone	Whole logistic model
Lifetime	Univariate association	< 0.0001	NS	NS	NS	NS	NS	-
history	Logistic regression	0.0002	NS	NS	NS	NS	NS	<0.0001
Lifetime anogenital	Univariate association	NS	NS	NS	NS	NS	NS	-
herpes history	Logistic regression	NS	NS	NS	NS	NS	NS	0.0068
Lifetime anogenital warts history	Univariate association	NS	NS	NS	NS	NS	NS	-
	Logistic regression	NS	NS	NS	NS	NS	NS	NS
Lifetime	Univariate association	0.0004	NS	NS	NS	NS	NS	-
history	Logistic regression	0.0330	NS	NS	NS	NS	NS	0.0030
Lifetime	Univariate association	NS	NS	NS	NS	NS	NS	-
history	Logistic regression	NS	NS	NS	NS	NS	NS	NS
Lifetime NSU history	Univariate association	0.0001	NS	NS	0.0165	NS	0.0185	-
	Logistic regression	0.0003	NS	NS	0.0313	NS	NS	0.0002

Table 15: Social correlates of sexually transmitted infection history. P values for significant (positive) associations according to the statistical methods listed in Table 14. \*Logistic regression models included all of the social variables. NS = no significant univariate association or no significant independent association in logistic regression model. Shading indicates significant independent associations that that remain significant after Bonferroni's Adjustment for six multiple comparisons (P = 0.0083)

# Correlates of depressive disorders

The associations identified between the presence of depressive disorders and the social variables (calculated according to the statistical methods described in Table 14) are shown in Table 16. As can be seen, in contrast to the data for sexually transmitted infections, *younger* age was associated with several of the depression measures. Further significant associations were seen between depressive diagnoses and several markers of social disadvantage.

Health characteristic	Association type	( <b>younger</b> ) Age	Not being employed	(lower) Income group	(lower) Educational attainment	('lower') Occupation type	Living alone	Whole logistic model
Current Major	Univariate association	< 0.001	0.0002	< 0.0001	0.0038	NS	NS	-
Depressive Episode	Logistic regression	0.0005	NS	0.0003	0.0213	0.0290	NS	(0.0574)
Current Dysthymic Disorder	Univariate association	NS	0.0113	< 0.0001	< 0.0001	(0.0518)	NS	-
	Logistic regression	NS	NS	0.0108	0.0007	NS	NS	0.0001
Either current	Univariate association	0.0010	0.0079	< 0.0001	0.0002	NS	0.0228	-
depressive disorder	Logistic regression	0.0036	NS	0.0007	0.0031	NS	0.0131	0.0002
Effective Zung score	Univariate association	0.0206	0.0012	< 0.0001	NS	NS	NS	-
	Logistic regression	0.0381	0.0335	NS	NS	NS	NS	< 0.0001

Table 16: Social correlates of depressive disorders and effective Zung score (see below). P values for significant associations according to the statistical methods listed in Table 14. \*Logistic regression models included all of the social variables. NS = no significant univariate association or no significant independent association in logistic regression model. Shading indicates significant independent associations in the logistic regression models and univariate associations that that remain significant after Bonferroni's Adjustment for six multiple comparisons (P = 0.0083)

## Zung depression rating scale

In addition to Prime-MD, the Zung Depression Rating Scale [Zung, 1983] was administered to participants who indicated either the presence of depressed feelings or reduced interest and pleasure in activities in their answers to the screening questions. The higher the score on this test, the greater the number and intensity of depressive symptoms reported.

For the purpose of this analysis an Effective Zung Score (EZS) has been calculated by employing the actual score for participants who answered a screening question affirmatively and completed the score, and allotting a score of 50 (the upper limit of normal for this test) to those who did not report the screening symptoms.

The EZS showed a reasonable correlation with a Prime-MD diagnosis of MDE (Spearman r = 0.473, P < 0.0001) and so was used to provide an interval measure of depression severity for the analysis for associated factors shown in Table 16. Its validity for this purpose is supported by its significant but weaker correlation with having any current depressive disorder (Spearman r = 0.307, P < 0.0001) and with the 'milder' but chronic condition of DD (Spearman r = 0.253, P < 0.0001).

#### Associations between depression and substance use levels

In separate analyses, each of the depression measures (current MDE, current DD, current depressive disorder and EZS) was assessed using the statistical techniques outlined in Table 14 for univariate association with the level of use of each of the substances considered later in the chapter. The results of this analysis are presented in Table 17. Since nine comparisons were drawn for each variable in this analysis, the Bonferroni Adjustment (see page 328) would suggest a 'P' value of 0.05/9 = 0.0056 as a more stringent marker for significance accounting for multiple comparisons (but see also page 353). Associations that reach this level are shaded in the table.

	Tobacco use	Alcohol use	Cannabis use	Nitrite use	Amphetamine use	LSD use	Ecstasy use	Heroin use	Any IDU
Current MDE	<0.0001	NS	0.0116	NS	0.0016	0.0003	0.0006	0.0062	0.0187
Current DD	NS	NS	0.0025	NS	0.0007	0.0006	0.0064	0.0002	0.0003
Current depressive disorder	0.0003	NS	0.0021	NS	0.0003	<0.0001	0.0034	0.0024	0.0069
EZS	0.0092	NS	NS	NS	0.0125	0.0097	0.0121	0.0315	0.0021

Table 17: Univariate association of depression markers with substance use levels by comparison of medians with Mann Whitney Test for presence or absence of disorders and Spearman's correlation for EZS. P values for significance of (positive) association are shown. NS = no significant univariate association. Shading indicates associations that remain significant after Bonferroni's Adjustment for nine multiple comparisons (P < 0.0056).

Multiple regression models were then constructed using multiple logistic regression for the dichotomous depression measures and a multiple linear regression analysis for Effective Zung Score. Models first were constructed incorporating all of the substance variables and then (second models) incorporating only the variables that showed univariate association with the outcome. The results of this analysis are summarised in Table 18. The 'Whole Model' column quotes the P value for goodness of fit for the multiple linear regression models and for the likelihood ratio for the multiple logistic regression models.

The 'disappearance' of association with amphetamines, LSD and ecstasy use in this analysis results for the cross correlation these variables with each other (see Table 13 on page 326) meaning that the use of each these substances is not independent of the use of the other two. Thus, no *independent* association with any of the drugs will be found. This lack of independence should not be taken necessarily to represent a lack of importance of the use of these substances in the production of the psychological health outcomes.

	Tobacco use	Alcohol use	Cannabis use	Nitrite use	Amphet- amine use	LSD use	Ecstasy use	Heroin use	Any IDU	Whole Model
Current MDE (AV)	0.0060	NS	NS	NS	NS	NS	NS	NS	NS	0.0002
Current MDE (Second Model)	0.0007	Excl.	NS	Excl.	NS	NS	NS	NS	NS	0.0001
Current DD (AV)	NS	NS	0.0214	NS	NS	NS	NS	NS	NS	0.0368
Current DD (Second Model)	Excluded		0.0173	Excl.	NS	NS	NS	NS	NS	0.0169
Current depressive disorder (AV)	0.0196	NS	NS	NS	NS	NS	NS	0.0465	NS	0.0005
Current depressive disorder (Second Model)	NS	Excl.	0.0073	Excl.	NS	NS	NS	0.0324	NS	0.0011
EZS (AV)	NS	NS	NS	NS	NS	NS	NS	NS	NS	0.0113
EZS (Second model)	0.0404		Excluded		NS	NS	NS	NS	NS	0.0059

Table 18: Association of depression markers with substance use levels in multivariate regression models including all dependent variables. P values for (positive) association. Shading indicates independent associations that are significant at the P < 0.0500 level. NS = no significant independent association.

#### Summary

The presence of diagnosable depressive disorders (as identified by Prime-MD) and the intensity of depressive symptoms (as measured by the EZS) both appear to be associated with a range of social factors. Lower income, lower levels of educational achievement and living alone all seem to be significantly related to at least some aspects of depressive symptomatology. Whether a person is employed and their occupational 'class' may also be associated but it may be that the major effect of these variables results from their relationship with income.

Major Depressive Episode seems to be consistently related to tobacco usage level and Dysthymic Disorder appears to be independently related to cannabis usage. In addition there may be a more general relationship between the use level of most of the drugs investigated and depressive symptoms that is not specific to the drug in question (and hence not seen as an independent association in multivariate analyses).

The comments on page 325 about the complexity surrounding the relationships between social factors, substance use and health outcomes should be borne in mind in the interpretation of these findings.

# Correlates of suicidal ideation

Among the listed social correlates, (younger) age (median ages: 37.1 vs 40.3, P = 0.0179 by MWT), (not having) employment (OR: 0.495, 95%CI: 0.309 to 0.794, P = 0.0033 by FET), and (lower) income group (median: \$4,001 - 9,000' vs \$18,001 - 22,000', P < 0.0001 by MWT), were associated in univariate analysis with the likelihood of reporting suicidal ideation in the two weeks prior to enrolment.

In a multiple logistic regression model including all of the social variables, only (younger) age at enrolment (P = 0.0205) showed an independent association, presumably because income and employment status are closely related to each other (Spearman r = 0.710; P < 0.0001 univariately). The associations were further investigated with logistic regression models including the three possible pairs of factors that were univariately associated with suicidal ideation. In a model including both age and employment status, both were significantly associated with suicidal ideation. In a model including age and income group, both were significantly correlated. In a model including income group and employment status but not age, however, only income group remained significantly associated with suicidal ideation. This suggests that there are independent associations with age and income and that the latter is confounded by association with employment in the full model.

In a separate analysis, recent suicidal ideation was not found to be significantly associated with the level of use of any of substances investigated.

# Correlates of anxiety disorders

## **Panic Disorder**

Among the listed social correlates, (not having) employment (OR: 0.418, 95%CI: 0.234 to 0.747, P = 0.0029 by FET) and (lower) income group (median: '9001 - 15,000' vs '18,001 - 22,000', P = 0.0025 by MWT), were associated in univariate analysis with the likelihood of having diagnosable Panic Disorder on enrolment. Alternative explanations for this relationship include that unemployment and low income are a causative factors in Panic Disorder, that people with the disorder are less able to obtain employment and thus have lower incomes or that the likelihood of being diagnosed with Panic Disorder and the social factors are related through another (unmeasured) variable. It may well be that each of these mechanisms is in action and that the relationship represents the kind of complex intertwining suggested by multi-level models of health production (see page 47).

In a multiple logistic regression model including all of the social variables, no individual factor showed significant *independent* association with the disorder, because of the correlation between income and employment (Spearman r = 0.710; P < 0.0001).

In a separate analysis, a diagnosis of panic disorder was found to demonstrate significant univariate correlation with levels of use of cannabis (P = 0.0100 by MWT); amphetamines (P = 0.0003 by MWT); LSD (P = 0.0002 by MWT); ecstasy (P = 0.0012 by MWT), heroin (P < 0.0001 by MWT), and injecting use of any drug (P < 0.0001 by MWT). In a multiple logistic regression model including all of the substance use variables, only injecting use of any drug demonstrated a significant independent association with a diagnosis of panic disorder (P = 0.0174), because of the close correlation *between* the use of many of the drugs showing univariate associations (see Table 13).

#### **Generalised Anxiety Disorder**

Among the listed social correlates, (not having) employment (OR: 0.448, 95%CI: 0.270 to 0.743, P = 0.0018 by FET) and (lower) income (median: `9001 - 15,000' vs `18,001 - 22,000', P = 0.0001 by MWT) were associated in univariate analysis with the likelihood of having diagnosable Generalised Anxiety Disorder on enrolment.

In a multiple logistic regression model including all of the social variables, only (lower) educational attainment (P = 0.0276) demonstrated a significant independent relationship with the likelihood of having GAD.

In a separate analysis, a diagnosis of GAD was found to demonstrate significant univariate association with levels of use of tobacco (P = 0.0225 by MWT); cannabis (P = 0.0380 by MWT) and heroin (P 0.0163 by MWT). In a multiple logistic regression model including all of the substance use variables, no individual variable demonstrated significant independent association with GAD diagnosis, most likely because of the significant correlation between many of the substance variables (see Table 13 on page 326).

## Correlates of substance use levels

In this section, the level of use of each of the substances as a dependent variable is correlated against the six social variables listed on page 325 as independent variables. The issue of multiple comparisons again needs to be borne in mind and the reader may chose to apply the more stringent P value suggested by the Bonferroni Adjustment discussed on page 328 (P < 0.0083) as the threshold for significance of univariate associations reported. Many of the associations reported reach this threshold but some do not and should thus be treated with caution. P < 0.0500 was used as the threshold for the multivariate analyses since the multiple comparisons problem is not relevant when these methods are employed.

## Tobacco

Among the social correlates listed on page 325, (younger) age (Spearman r = -0.126, P = 0.0034), (not having) employment (P < 0.0001 by MWT), (lower) income (Spearman r = -0.300, P < 0.0001), (lower) educational attainment (Spearman r = -0.214, P < 0.0001) and ('lower') occupational category (Spearman r = -0.148, P = 0.0005) were significantly associated in univariate analysis with the level of tobacco use reported on enrolment.

In a multiple linear regression model incorporating all of the listed social variables, (younger) age (P = 0.0031), (lower) level of educational attainment (P = 0.0086) and (lower) income (P < 0.0001) all showed significant independent associations with tobacco use level.

## Alcohol

Among the listed social correlates, (younger) age (Spearman r = -0.0847, P = 0.0488), (*having*) employment (P = 0.0085 by MWT) and (*higher*) income group (Spearman r = -0.0997, P = 0.0202) were significantly associated in univariate analysis with the level of alcohol use reported on enrolment.

In a multiple linear regression model incorporating all of the listed social variables, only (younger) age (P = 0.0179) showed a significant independent association with alcohol use levels. In simpler models including age and either employment or income group, the last two variables showed an association with alcohol use that was independent of age.

The 'inverse' relationship<sup>\*</sup> of alcohol use level with employment and income is interesting. A multi-level approach could suggest mechanisms such as financial capacity to purchase large quantities of alcohol or decisions to use a drug (alcohol) that (within limits) provides rapid recovery allowing the user to work the following day, that might be woven into the production of this health outcome.

 $<sup>^{\</sup>ast}$  In comparison with the other health conditions investigated.

## Cannabis

Among the listed social correlates, (younger) age (Spearman r = -0.272, P < 0.0001), (not having) employment (P = 0.0116 by MWT), (lower) income (Spearman r = -0.2263, P < 0.0001), (lower) education level (Spearman r = -0.0866, P = 0.0440) and ('lower') occupational group (Spearman r = -0.0863, P = 0.0447) were significantly associated in univariate analysis with the level of cannabis use reported on enrolment.

In a multiple linear regression model incorporating all of the listed social variables, (younger) age at enrolment (P < 0.0001) and (lower) income (P = 0.0045) showed significant independent associations with cannabis use levels.

## Nitrites

None of the listed social correlates was significantly associated in either univariate analysis or a multiple linear regression model with the level of nitrate use reported on enrolment.

## Amphetamines

Among the listed social correlates, (younger) age (Spearman r = -0.277, P < 0.0001), (not having) employment (P = 0.0061 by MWT), (lower) income (Spearman r = -0.193, P < 0.0001) and (lower) education level (Spearman r = -0.0866, P = 0.0440) were significantly associated in univariate analysis with the level of amphetamine use reported on enrolment.

Interestingly, in a multiple linear regression model including all of the variables, (*'higher'*) occupational category (for people who were working) demonstrated significant independent association (at a P value of 0.0026) with amphetamine usage, that was not apparent in univariate analysis, but none of the other social variables showed independent associations.

While this may, of course, be a chance finding, it raises the question of whether there are two cultural 'spaces' for amphetamine use among homosexually active men. One might be (like cannabis) among people on low incomes, while the other might be among employed people in 'higher' (managerial and professional) positions, perhaps in association with interstate travel to events such as Mardi Gras (where amphetamine use is, anecdotally, very prominent).

#### LSD

Among the listed social correlates, (younger) age (Spearman r = -0.277, P < 0.0001), (not having) employment (P = 0.0116 by MWT) and (lower) income (Spearman r = -0.210, P < 0.0001) were significantly associated in univariate analysis with the level of LSD use reported on enrolment.

In a multiple linear regression model including all of the social variables, younger age (P < 0.0001) and lower income (P = 0.0003) were independently associated with LSD use, but (as with amphetamine) so was 'higher' occupation type among people who were working (P = 0.0001), despite the absence of a univariate association. The discussion above on the sociology of amphetamine usage patterns might well also apply to this drug (and the next), which are also popular at dance parties.

#### **Ecstasy**

Among the listed social correlates, (younger) age (Spearman r = -0.344, P < 0.0001), (not having) employment (P = 0.0270 by MWT), (lower) income (Spearman r = -0.172, P < 0.0001) and (*'higher'*) occupation type (Spearman r = 0.120, P = 0.0051) were significantly associated in univariate analysis with the level of ecstasy use reported on enrolment. A multiple linear regression model including all of the social variables confirms significant independent associations between ecstasy use levels and (younger) age, (lower) income but ('higher') occupation type.

The presence of this pattern for all three of the drugs that are, anecdotally, popular at interstate party events (amphetamines, LSD and ecstasy) provides support for the 'two cultural spaces' theory suggested above. The fact that ecstasy (which is anecdotally the most popular 'party' drug) showed the strongest association with 'higher' occupational type (P < 0.0001 in the multivariate model and, uniquely, a discernable univariate association) lends real support to the 'two cultural spaces' theory advanced under 'amphetamines' above.

#### Heroin

Among the listed social correlates, (younger) age (Spearman r = -0.1024, P = 0.0171), (not having) employment (P = 0.0002 by MWT) and (lower) income (Spearman r = -0.197, P < 0.0001) were significantly associated in univariate analysis with the level of heroin use reported on enrolment.

In a multiple linear regression model including all of the listed social variables, (younger) age (P = 0.0234) and (lower) income group (P = 0.0471) showed a significant independent association with heroin use level.

#### Injecting use of any illicit drug

Among the listed social correlates, (younger) age (Spearman r = -0.206, P < 0.0001), (not having) employment (P < 0.0001 by MWT) and (lower) income (Spearman r = -0.210, P < 0.0001) were significantly associated in univariate analysis with the level of ecstasy use reported on enrolment. In a multiple linear regression model including all of the social variables, (younger) age (P < 0.0001) and ('higher') occupation type (P = 0.0076) showed significant independent associations with level of injecting drugs use. The latter finding, despite the absence of a univariate correlation, is consistent with the injecting use of amphetamine in 'two cultural spaces' described above.

# Correlates of sf36 scores

Participants' scores (out of 100, with higher scores indicating better self-rated health) for each domain of the Short Form  $36^*$  were compared univariately for association with each of the social factors listed on page 325 and then a linear regression model was constructed to compare each domain with all of the social factors acting together. In a separate analysis the score for each domain was compared with the levels of use of each of the substances investigated both univariately and then multivariately. For the univariate analyses, the issue of multiple comparisons needs to be borne in mind and the reader may chose to apply the more stringent thresholds for significance indicated by the Bonferroni Adjustment discussed on page 328. For the social factors analysis (six comparisons) this threshold is P < 0.0083, and for the substance use analysis (nine comparisons) it is P < 0.0056.

## **Physical Function**

Participants' scores in the Physical Function domain of sf36 were associated in univariate analysis with (younger) age (Spearman's r = -0.123, P = 0.0051), (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.218, P < 0.0001), (higher) educational attainment (Spearman's r = 0.116, P = 0.0081), and (not) living alone (P = 0.0020 by MWT). In the multiple linear regression model incorporating all of the listed social variables, (younger) age (P = 0.0215) and (having) employment (P = 0.0007) showed significant independent association with higher scores.

In a separate analysis, Physical Function scores were found to show significant univariate correlation only with (lower) tobacco use (Spearman's r = -0.203, P < 0.0001) among the listed substances.

<sup>\*</sup> See page 234 for details of the scale 340

In a multiple linear regression model including use level of all of the substances, (lower) tobacco use level demonstrated a significant independent association with higher Physical Function scores (P = 0.0002), as did (*higher*) levels of alcohol use (P = 0.0259).<sup>\*</sup> Once again, this may be a chance finding but it may also lend support to the belief that there may be health benefits from a moderate alcohol intake compared with abstinence.(Gronbaek, 2001) Less obvious mechanisms might equally be involved, such as the association of higher levels of Physical Function with employment and higher income leading to men with higher scores being more able to afford to attend venues where they might drink alcohol.

## Role limitation due to physical health ('Role Physical')

The Role Physical domain of sf36 purports to measure the extent to which the respondent's fulfilment of usual responsibilities is perceived as having been limited by their physical health. As usual for the sf36, higher scores indicated better health and thus *less* limitation of role fulfilment on this basis.

Participants' scores in the Role Physical domain were associated in univariate analysis with (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.208, P < 0.0001), and (not) living alone (P = 0.0127 by MWT). Perhaps surprisingly no association with age was evident. In a multiple linear regression model incorporating all of the listed social variables, only (having) employment showed significant independent association with higher scores (P = 0.0002).

In a separate analysis, Role Physical scores were found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.0990, P = 0.0244), (lower) alcohol use (Spearman's r = 0.0875, P = 0.0468), and (lower) cannabis use (Spearman's r = -0.0883, P = 0.0448).

<sup>&</sup>lt;sup>\*</sup> In the univariate analysis, (higher) alcohol use levels also showed a level of association with Physical Function scores that approached the significance level (Spearman's r = 0.0771, P = 0.0798)

In a multiple linear regression model including use level of all of the substances, only (lower) alcohol use level (P = 0.0002) demonstrated a significant independent association with higher Role Physical scores (that is with less perceived limitation of function due to physical ill-health).

#### **General Health**

Participants' scores in the General Health domain of sf36 were correlated in univariate analysis with (perhaps surprisingly, *older*) age (Spearman's r = 0.0993, P 0.0240), (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.191, P < 0.0001), and (not) living alone (P = 0.0002 by MWT). In a multiple linear regression model incorporating all of the listed social variables, (older) age (P = 0.0018), (higher) income (P = 0.0228), ('higher') occupation level (P = 0.0047) and (not) living alone (P = 0.0003) all showed significant independent association with higher self-rated General Health scores.

In a separate analysis, General Health scores were found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.153, P = 0.0005), (lower) cannabis use (Spearman's r = -0.138, P = 0.0016), (lower) amphetamine use (Spearman's r = -0.145, P = 0.0010), (lower) LSD use (Spearman's r = -0.146, P = 0.0009), (lower) ecstasy use (Spearman's r = -0.0938, P = 0.0329), (lower) heroin use (Spearman's r = -0.121, P = 0.0060) and (lower) injecting use of any drug (Spearman's r = -0.101, P = 0.0212). In a multiple linear regression model including use level of all of the substances, only (lower) tobacco use level (P = 0.0124) demonstrated a significant independent association with higher General Health scores (that is with better perceived general health).

#### **Bodily Pain**

Participants' scores in the Bodily Pain domain of sf36 (in which, like the other domains, higher scores mean better health and so *less* pain) were correlated in univariate analysis with (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.185, P < 0.0001), and (not) living alone (P = 0.0109 by MWT).

In a multiple linear regression model incorporating all of the listed social variables, (having) employment (P = 0.0015), and (not) living alone (P = 0.0264) showed significant independent association with higher Bodily Pain health scores.

In a separate analysis, Bodily Pain scores were also found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.111, P = 0.0115), (*higher*) alcohol use (Spearman's r = 0.1020, P < 0.0001, (lower) cannabis use (Spearman's r = -0.178, P = 0.0016), (lower) heroin use (Spearman's r = -0.0923, P = 0.0361) and (lower) injecting use of any drug (Spearman's r = -0.0900, P = 0.0411). In a multiple linear regression model including use level of all of the substances, (higher) alcohol use (P = 0.0122), (lower) cannabis use (P < 0.0001) and (lower) heroin use (P = 0.0098) demonstrated a significant independent associations with higher Bodily Pain scores (that is with better perceived health and presumably less experienced pain). The discussion of the relationship with higher levels of alcohol use considered for Physical Function on page 341 may be equally relevant for this parameter.

#### Vitality

Participants' scores in the Vitality domain of sf36 were correlated in univariate analysis with (*higher*) age at enrolment, (Spearman's r = 0.158, P = 0.0003), (having) employment (P = 0.0004 by MWT) and (higher) income group (Spearman's r = 0.188, P < 0.0001). In the multiple linear regression model incorporating all of the listed social variables, (higher) age (P < 0.0001), and ('higher') occupation group (P = 0.0382) showed significant independent associations with higher Vitality health scores. The association with older age for this and the General Health score is somewhat surprising. It emphasises that subjective scoring has an implicit element of comparison of like with like. That is, men of a particular age may compare their self perceptions of health or vitality with others of their own age and their ratings will probably be related to aspects of their self regard at the time, as well as their 'pure' subjective experiences of wellbeing.

In a separate analysis, Vitality scores were found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.146, P = 0.0009), (lower) cannabis use (Spearman's r = -0.113, P = 0.0105), (lower) amphetamine use (Spearman's r = -0.132, P = 0.0026), (lower) LSD use (Spearman's r = -0.100, P = 0.0224), (lower) ecstasy use (Spearman's r = -0.0920, P = 0.0366), (lower) heroin use (Spearman's r = -0.108, P = 0.0142) and (lower) injecting use of any drug (Spearman's r = -0.0962, P = 0.0288). In a multiple linear regression model including use level of all of the substances, only (lower) tobacco use (P = 0.0143) demonstrated a significant independent association with higher Vitality scores.

#### **Social Function**

Participants' scores in the Social Function domain of sf36 were correlated in univariate analysis with (*higher*) age at enrolment, (Spearman's r = 0.176, P < 0.0001), (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.286, P < 0.0001), (higher) educational attainment (Spearman's r = 0.110, P = 0.0120), and (not) living alone (P = 0.0130 by MWT). In the multiple linear regression model incorporating all of the listed social variables, (higher) age (P < 0.0001), (having) employment (P = 0.0374), (higher) income (P = 0.0203) and (not) living alone (P = 0.0205) showed significant independent associations with higher Social Function scores.

In a separate analysis, Social Function scores were also found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.189, P < 0.0001), (lower) cannabis use (Spearman's r = -0.141, P = 0.0013), (lower) amphetamine use (Spearman's r = -0.169, P = 0.0001), (lower) LSD use (Spearman's r = -0.126, P = 0.0040), (lower) ecstasy use (Spearman's r = -0.139, P = 0.0015), (lower) heroin use (Spearman's r = -0.126, P = 0.0040) and (lower) injecting use of any drug (Spearman's r = -0.151, P = 0.0006). In a multiple linear regression model including use level of all of the substances, (lower) tobacco use and (higher) alcohol use demonstrated significant independent associations with higher Social Function scores.

#### Role limitation due to emotional health ('Role Emotional')

The Role Emotional domain of sf36 purports to measure the extent to which the respondent's fulfilment of usual responsibilities is perceived as having been limited by their emotional health. As usual for the sf36, higher scores indicated better health and thus *less* limitation of role fulfilment on this basis. Participants' scores for Role Emotional were correlated in univariate analysis with (higher) age at enrolment, (Spearman's r = 0.186, P < 0.0001), (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.301, P < 0.0001), and (higher) educational attainment (Spearman's r = 0.119, P = 0.0069). In the multiple linear regression model incorporating all of the listed social variables, (higher) age (P < 0.0001), (higher) income (P = 0.0047) and (not) living alone (P = 0.0255) showed significant independent associations with higher Role Emotional scores.

In a separate analysis, Role Emotional scores were found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.192, P < 0.0001), (lower) cannabis use (Spearman's r = -0.180, P < 0.0001), (lower) amphetamine use (Spearman's r = -0.149, P = 0.0007), (lower) LSD use (Spearman's r = -0.150, P = 0.0006), (lower) ecstasy use (Spearman's r = -0.137, P = 0.0018), (lower) heroin use (Spearman's r = -0.161, P = 0.0002) and (lower) injecting use of any drug (Spearman's r = -0.140, P = 0.0014). In a multiple linear regression model including use level of all of the substances, (lower) tobacco use (P = 0.0033), (lower) cannabis use (P = 0.0290) and (lower) heroin use (P = 0.0408) all demonstrated significant independent associations with higher Role Emotional scores.

#### **Mental Health**

Participants' scores in the mental domain of sf36 were correlated in univariate analysis with (higher) age at enrolment, (Spearman's r = 0.189, P < 0.0001), (having) employment (P < 0.0001 by MWT), (higher) income group (Spearman's r = 0.282, P < 0.0001), (higher) educational attainment (Spearman's r = 0.103, P = 0.0192), and (not) living alone (P = 0.0440 by MWT).

In the multiple linear regression model incorporating all of the listed social variables, (higher) age (P < 0.0001), and (higher) income (P = 0.0013) showed significant independent associations with higher Mental Health scores.

In a separate analysis, Mental Health scores were found to show significant univariate correlation with (lower) tobacco use (Spearman's r = -0.1662, P = 0.0001), (higher) alcohol use (Spearman's r = 0.0877, P = 0.0462, (lower) cannabis use (Spearman's r = -0.152, P = 0.0005), (lower) amphetamine use (Spearman's r = -0.169, P = 0.0001), (lower) LSD use (Spearman's r = -0.192, P < 0.0001), (lower) ecstasy use (Spearman's r = -0.109, P = 0.0129), (lower) heroin use (Spearman's r = -0.172, P < 0.0001) and (lower) injecting use of any drug (Spearman's r = -0.138, P = 0.0017).

In a multiple linear regression model including use level of all of the substances, (lower) tobacco use (P = 0.0018), (higher) alcohol use (P = 0.0239) and (lower) heroin use (P = 0.0031) all demonstrated significant independent associations with higher Mental Health scores.

#### Summary

Participant scores on all of the sf36 scales were significantly correlated with social variables, most particularly with income, supporting the hypothesis that social disadvantage contributes to the production of ill health among the homosexually active men in the Care and Prevention Programme cohort.

The association between sf36 scores and older age, seen in the General Health, Vitality, Social Function, Role Emotional and Mental Health domains, appears at first to be counter-intuitive. Such a relationship is certainly not seen in the (detailed) population norms for American males provided in the sf36 manual.(Ware, 1993) In these tables, sf36 scores either *decrease* with age (particularly for the more 'physical' scores like Physical Function<sup>\*</sup> and Role Physical) or else do not demonstrate a particular relationship with age.

 $<sup>^{*}</sup>$  Even in the C&PP results the Physical Function domain is related to *younger* age. 346

The relative consistency of this relationship in the C&PP cohort across multiple sf36 domains suggests a systematic association and invites speculation as to its meaning. One candidate explanation is that the stress associated with 'coming out' (see page 134) in adolescence or early adulthood leaves an impact on the self-perceived health of many homosexually active men that does not dissipate for several years. In this scenario it is only with life experience and 'maturity' that the health impacts of problematic parental relationships and discriminatory experiences during coming out are mitigated.

# Extended sociohistorical correlates

When the high prevalences of depressive disorders and anxiety disorders, and the high levels of substance use, among enrolees were fully recognised, the Care and Prevention Programme team, under the author's leadership, set out to investigate the possible causes of these outcomes further. As a consequence, at the Second Review of participants, conducted an average of 36 months after enrolment, additional questions were included to elucidate participants' experiences including the following:

- Problematic parental relationships in childhood
- Recollection of childhood sexual abuse (CSA)
- Experience of non-consensual sex in adulthood
- Recent experience of violence and verbal abuse

Participants were also asked at this review about a history of attempted suicide (see page 297).

The additional questions were developed by the Programme team on the basis of the literature and informal discussion with participants about their experiences. These questions were not formally assessed for reliability or validity but the general statements on this topic on page 236 apply to them. They are reproduced in full, together with the available responses in Appendix 3 (see page 481).

Because these questions were introduced at the Second Review, the population of homosexually active men who had completed them at the time of analysis was smaller than the total of all enrolees (see page 385). 210 homosexually active men had completed the Second Review to 30/6/2003, of whom 79 were HIV+ and 130 were HIV -/? at the time of review. Two of these men had been diagnosed HIV+ between enrolment and review.

Because of the different samples involved, and because these additional data were gathered prospectively with the specific intention of undertaking this analysis, the relationships between these sociohistorical variables and the health characteristics of interest (listed on page 324) are analysed here separately.

Because engagement with the C&PP was associated with improvement in many aspects of health status for participants (see Part 4), each participant's report at the Second Review about these earlier experiences has generally been compared with the person's health characteristics *on enrolment* to maximise the likelihood of any association being detected.<sup>\*</sup>

## **Parental relationships**

Participants were asked to nominate which of the statements below best described their relationship with each biological parent during their early childhood. 209 men answered these questions.

For paternal relationships, the numbers and proportions providing each answer are shown in Table 19 on page 349.

<sup>&</sup>lt;sup>\*</sup> The exception is that for comparisons with Victimisation and Abuse Score (see page 350), which encompasses only the prior year, health characteristics at the Second Review were used for comparison.

$\overline{\ }$	Statement selected	Number	%
1	He was not around during my early childhood	27	13%
2	He was emotionally distant during my early childhood	55	26%
3	I remember an "average" relationship with him	46	22%
4	He was a strict disciplinarian	24	11%
5	We had a warm close relationship during my early childhood	32	15%
6	None of the above is appropriate	25	12%
	Total	209	100%

Table 19: Participant choice of descriptor for early childhood relationship with father

Because of the literature suggesting that recalling one's father to have been emotionally distant may be related to psychological difficulties in gay identified men (see page 353), these responses were transformed for the analysis into a dichotomous variable by separating men who chose response 2 from the remainder.

For maternal relationships, the numbers and proportions providing each answer are shown in the following table:

	Statement selected	Number	%
1	She was not around during my early childhood	4	2%
2	She was emotionally distant during my early childhood	16	8%
3	I remember an "average" relationship with her	40	19%
4	She was a strict disciplinarian	15	7%
5	We had a warm close relationship during my early childhood	119	57%
6	None of the above is appropriate	15	7%
	Total	209	100%

Table 20: Participant choice of descriptor for early childhood relationship with mother

These responses were also transformed into a dichotomous variable using the same method as for paternal relationships.

#### Recollection of childhood sexual abuse (CSA)

As outlined on page 298, 49 of the 210 men reviewed (23%) reported a recollection of sexual abuse before the age of eighteen. 26 men (12%) reported such an experience below the age of ten years, 31 men (15%) above the age of 10 (including 8 men [4%] who reported abuse in both age ranges). 15 men (7%) reported abuse by a family member and 43 (21%) by an outsider (including 9 men [4%] who reported both experiences).

Report (or not) of a recollection of any childhood sexual abuse (as defined by the participant - see question used in Appendix 3) was recorded as a dichotomous variable for the analysis that follows.

#### Non-consensual sex in adulthood

24 of the 210 men reviewed (11%) reported having been forced to engage in sexual activity without their consent since their 18th birthday. This was also recorded as a dichotomous variable for the analysis of correlates.

#### Recent experience of violence and verbal abuse

54 of the 210 reviewed participants (26%) reported having been subject to verbal abuse by a stranger in the prior year, 24 (11%) had experienced threats of violence from a stranger and 9 (4%) reported having experienced actual physical violence by a stranger in the prior year. These experiences were compared with health indices at the Second Review rather than at enrolment because of the time frame of the adverse experience enquired about.

A Violence & Abuse Score (VAS) was formulated by allotting 5 points for a reported experience of actual violence, 2 points for a threat of violence and 1 point for verbal abuse. This score was used as an interval measure in the analysis.

The statistical methods described in Table 14 on page 327 were also employed for this analysis of extended sociohistorical correlates of health characteristics.

The multiple comparisons problem (see page 328) is felt not to be relevant in this instance since the questions were formulated and asked prospectively, to test for relationships between each sociohistorical factor and the pre-determined health characteristics. A very conservative position on the issue, though, would include concern about each factor being applied to multiple health characteristics - even though this analysis was planned prospectively. Given the large number of health characteristics (28 if each sf36 scale is counted) with which the factors have been compared, the application of a Bonferroni Adjustment to the P values (vielding a threshold of P < 0.0500 / 28 = 0.0018) would eradicate many of the associations that will be reported in this section. To have done so, particularly in project such as this, which is exploring relationships between factors, would, as Rothman pointed out, have markedly increased the risk of a 'type II' error (failing to recognise a meaningful association as significant) and so this approach has not been adopted.(Rothman, 1990) This concern is discussed more fully in the Summary below. The issue should, however, be borne in mind when considering the meaning of the findings.

The results of these analyses are presented in Table 21 on page 352. All of the relationships reported represent positive associations between the social condition and the (ill-) health outcome. For the sf36 scores, which rate 'good' health, such an association appears as a negative relationship.

Health	Emotionally	Emotionally	Childhood	Non-consensual	Victimisation and
Characteristic	Distant Father	Distant Mother	Sexual Abuse	sex as adult	Abuse Score
Syphilis Hx	NS	NS	NS	NS	NS
A/gen HSV Hx	NS	NS	NS	NS	NS
A/gen warts Hx	NS	0.0138	0.0388	NS	NS
Gonorrhoea Hx	NS	NS	NS	NS	NS
Chlamydia Hx	NS	NS	NS	NS	NS
NSU Hx	NS	NS	NS	NS	NS
MDE	0.0003	NS	0.0007	NS	NS
DD	0.0241	NS	0.0358	NS	0.0257
Suicidal Ideation	NS	NS	0.0135	NS	NS
Panic Disorder	NS	(0.0787)	NS	NS	NS
GAD	0.0215	(0.0515)	0.0319	0.0297	NS
Tobacco use	NS	NS	(0.0595)	(0.0629)	NS
Alcohol use	NS	NS	NS	NS	NS
Cannabis use	NS	NS	NS	NS	NS
Nitrite use	NS	NS	NS	NS	NS
Amphet. use	(0.0863)	NS	NS	NS	NS
LSD use	NS	NS	NS	NS	NS
Ecstasy use	NS	NS	NS	NS	NS
Heroin use	NS	NS	NS	NS	NS
Inject. drug use	NS	NS	NS	NS	NS
sf36 Phys. Func.	NS	NS	NS	NS	0.0126 (NEG)
sf36 Role Phys.	NS	NS	NS	NS	0.0227 (NEG)
sf36 Bodily Pain	NS	NS	NS	NS	NS
sf36 Gen Health	0.0449 (NEG)	NS	0.0210 (NEG)	NS	0.0364 (NEG)
sf36 Vitality	0.0084 (NEG)	NS	0.0050 (NEG)	NS	0.0020 (NEG)
sf36 Soc. Func.	0.0018 (NEG)	NS	0.0169 (NEG)	NS	0.0002 (NEG)
sf36 Role Emot.	0.0084 (NEG)	NS	0.0041 (NEG)	NS	0.0002 (NEG)
sf36 Ment. HIth	0.0001 (NEG)	(0.0566) (NEG)	0.0030 (NEG)	(0.0608) (NEG)	0.0017 (NEG)

Table 21: Relationships between health characteristics and extended sociohistorical correlates (univariate analyses). Figures indicate P values. N = 210. P values between 0.0500 and 0.1000 included in paretheses for interest. '(NEG)' indicates a negative association.'

## Summary

The analysis presented in this section suggests that there are meaningful relationships between health outcomes and some of the life experiences studied.

Some of these relationships, such as those between a distant paternal relationship or CSA history on the one hand and Major Depressive Episode on the other, as well as those between Dysthymic Disorder and the VAS, appear to be quite robust. Their P values would remain significant even accounting for the multiple comparisons issue discussed on page 328.

<sup>\*</sup> Please note that these associations are 'negative' because sf36 scales measure better health as a higher number. All of the significant associations identified in the table show a relationship between the presence or magnitude of the sociohistorical factor and *poorer* health.

For others the relationship, if any, appears to be relatively subtle and the P values do not hold up to the more stringent thresholds demanded by a Bonferroni Adjustment. Rothman,(Rothman, 1990) and more recently Perneger have argued that such thresholds are not required or appropriate, especially for projects that seek to explore the associations of a health outcome. As Perneger puts it:

Bonferroni adjustments imply that a given comparison will be interpreted differently according to how many other tests were performed. For example ... a patient's packed cell volume might be abnormally low, except if the doctor also ordered a platelet count, in which case it could be deemed normal. Surely this is absurd, at least within the current scientific paradigm. Evidence in data is what the data say – other considerations, such as how many other tests were performed, are irrelevant.(Perneger, 1998 1237)

With this controversy in mind, what can be said is that these analyses raise interesting possibilities in terms of the relationship between life experiences and health characteristics, of which sense can be made in Krieger's ecosocial model (see page 47). They cannot, however, be considered to be *established* associations in the absence of replication in specifically designed studies.

Report of childhood sexual abuse and description of one's father as emotionally distant both seem to contribute to emotional ill-health by a variety of measures. The psychological consequences of sexual abuse have been well documented,(Arnow, 2004; Johnson, 2004) and the prevailing view of its importance is borne out by the results among reviewed men in the cohort.

The apparently pervasive effect of an 'emotionally distant' father is perhaps somewhat more surprising. Richard Isay, who was the first gay-identified person to be admitted to psychoanalytic training in the United States, has argued that the childhood relationships between boys who are destined to be same sex attracted and their father differs from those of other boys because their primordial 'sexual orientation' reverses the oedipal complex and may also be associated with gender atypical behaviour. He goes on to suggest that:

the frequent description by a gay man of his father as detached, absent, or hostile stems ... [in part] ... from the actual withdrawal of the father from his homosexual son once he becomes aware that his child is not acting like other boys his age or because of his own anxiety over the intensity of his son's attachment to him ... The withdrawal of the father, which is invariably experienced as a rejection, may be the cause of the poor self-esteem and the sense of inadequacy felt by some gay men.(Isay, 1989 34)

The observed relationships between recollection of an 'emotionally distant' relationship with the father and psychological disorders, especially depression, would be predicted by Isay's hypothesis.

## Discussion

Several of the health inequalities identified in Part 3 do appear to be associated with social variables (like low income, unemployment or reduced educational attainment), with substance use levels (some of which are themselves related to social variables) and with life experiences such having had an emotionally distant father or having recently experience of violence or abuse from strangers.

Most Australians would be likely to consider violence and abuse directed toward anyone in our country to be 'unjust or unfair'. Such experiences are also clearly 'unnecessary and avoidable' if perpetrators change their behaviour or society affords appropriate protections. Thus, to the extent that violence and abuse of people believed to be gay-identified or homosexually active is actually causative of the associated health impairment observed, such impairment would meet Whitehead's definition of health *inequity* (see page 39). Such causality will always be difficult to prove definitively, but as a theory it can easily be made sense of in terms of multi-level models of health causation. It also seems to adhere to Occam's razor as the simplest explanation for the observed phenomenon.

Whether the emotional rejection of gender atypical boys by their fathers postulated by Isay is also unfair might be slightly more controversial. Notions of 'toughening up' young males are deeply ingrained in Australian masculine culture and some would consider failure to respond negatively to 'effeminate' behaviour in boys to imply encouragement and thus to be undesirable. There are three ethical problems with this position.

The first is that the provision of unconditional positive regard and affection to children may be a fundamental human right. The Universal Declaration of Human Rights provides the foundation for this belief, (United Nations, 1948) but the rights of children are spelled out more fully in the Declaration of the Rights of the Child, proclaimed by United Nations General Assembly in 1959.

The relevant elements of this declaration would seem to be Principle 2, which states [in part]:

The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity, (United Nations, 1959)

Principle 6, which says [in part]:

The child, for the full and harmonious development of his personality, needs love and understanding. He shall, wherever possible, grow up in the care and under the responsibility of his parents, and, in any case, in an atmosphere of affection and of moral and material security,

Principle 9 which includes:

The child shall be protected against all forms of neglect, cruelty and exploitation

and Principle 10 which states:

The child shall be protected from practices which may foster racial, religious and any other form of discrimination. He shall be brought up in a spirit of understanding, tolerance, friendship among peoples, peace and universal brotherhood, and in full consciousness that his energy and talents should be devoted to the service of his fellow men.

While some might argue that discouragement of behaviours indicative of sexual diversity might be necessary to the 'moral security' and development 'in a normal manner' of a child, this position is hard to sustain the face of an exhortation to protect her or his 'freedom and dignity', to provide 'love and understanding', to 'protect against all forms of ... cruelty' and to foster 'understanding' and 'tolerance' and 'universal brotherhood'. A father who responds to his gender atypical son through emotional withdrawal would seem to be breaching several principles of this Declaration.

The second moral problem is that the categorisation of particular behaviours as gender appropriate relies only on tradition and itself has no ethical or philosophical basis without resort to arbitrary external codes. Thus, since young children are yet to adopt any arbitrary positions themselves, no justification can be made for abrogating their human rights 'for their own good'.

The third moral problem is with the question or voluntariness. Gender typical behaviours are not completely voluntary and in children may not even be largely voluntary. Thus a paternal strategy that uses withdrawal of affection as a tool to modify such behaviour will be ineffective even in its own (probably immoral) terms. This further undermines the legitimacy of such a course. As has been argued earlier with regard to frankly homosexual expression in adults (see page 125), this third argument becomes irrelevant if the view offered on the second problem is adopted.

Thus, many would reach the conclusion that the rejecting father of whom Isay speaks has acted unfairly and unjustly. Similarly, his actions were unnecessary and avoidable. So, to the extent that Isay is right about such rejection causing reduced emotional wellbeing, the depression, dysthmia, anxiety and reduced self-rated health that has been seen to be associated with the father's actions meets the definition of health inequity.

The question of whether social factors such as unemployment, low income, lower educational attainment as well as less remunerative and less fulfilling employment for those who are working, to the extent that their relationship with ill-health is causative, are 'unfair or unjust' is probably quite contentious in our late modern capitalist country. Principles of 'equality' (such as those espoused by Jesus of Nazareth and Karl Marx) have been replaced for many by ideas of 'equal opportunity', a framework to which even Whitehead refers when she says that under a system of health equity 'ideally everyone should have a fair opportunity to attain their full health potential'.(Whitehead, 1992 433)

But even under this individually-oriented, neo-liberal view of the world, homosexually active men who experience unemployment, low income, lower educational attainment or less challenging employment may be in that position because they have been denied equality of opportunity and thus they may be seen as having been treated unfairly.

In a 1998 survey of 748 same sex attracted Australians aged 14-21, of whom 49% were male, conducted by Hillier and colleagues, almost a third (29%) 'reported that they had been unfairly treated because of their sexuality'.(Hillier *et al.*, 1998 33)

Participants were recruited through national youth magazines and via the internet which, as discussed previously (see page 182), tends to bias in favour of enrolling relatively advantaged subjects. Thus, the rate of experience of discrimination is probably an underestimate. It should also be recognised that a further 33% of respondents in the study had not disclosed their same sex attraction to anyone, some perhaps because of fear of unfair treatment. Participants reported experiencing discrimination in a variety of settings but most notably at school and in the workplace. The study also asked about violence and abuse. 52% of male respondents reported having been verbally abused and 13% 'had been physically assaulted because of their sexual orientation'.(Hillier *et al.*, 1998 34) 81% of boys who reported abuse said that they had been abused at school.

Given this picture, it is difficult to conclude that Australian men of sexual diversity have enjoyed equality of educational opportunity. Impaired study performance and even outright school avoidance would seem likely to be an inevitable consequence of this level of harassment for a proportion same sex attracted boys. What is remarkable, perhaps, is that many such men do manage to complete an education satisfactorily.

The impact of discrimination, abuse and violence would be expected to disadvantage homosexually active men as a group in the educational arena. Further, they are likely also to experience similar unfair treatment in recruitment for employment and in the workplace. In a 1999 survey of 900 people of sexual diversity (including 416 men) recruited mostly through gay community events in New South Wales and Victoria, 52% reported that they 'had been the target of homophobic behaviour or harassment, had been treated prejudicially or been denied particular benefits available to heterosexual work colleagues in their current workplace'.(Irwin, 1999 28) A further 37% of this sample believed that they 'may have' experienced this treatment. In the same study, 145 respondents (17%) 'considered they had been refused a job on the basis of their homosexuality or transgender identity<sup>\*</sup>' and an additional 141 (17%) considered that they 'may have been refused a job' for this reason.(Irwin, 1999 37).

<sup>&</sup>lt;sup>\*</sup> The study included 59 people who identified as transgender.

In response to a separate question, 16% of respondents 'considered that they had not been promoted because of their homosexuality or gender identity'.

Some of these findings were confirmed in a further survey with a similar sampling methodology, but confined to Victoria, the following year. This study had 929 respondents (including 458 males), of whom 375 (40%) reported having 'experienced discrimination relating to their employment'. (Victorian Gay and Lesbian Rights Lobby, 1999 46) For 292 people (31%) this had occurred in the preceding five years. This discrimination reportedly took forms including harassment by the employer or fellow workers, sacking or pressure to leave, refusal for a job, a lack of promotion and refusal of a raise.

It needs to be recognised that what has been reported in these studies is only the workers' views of what has transpired. Some respondents may have been mistaken or may have ascribed treatment that was actually related to other factors to heterosexism. None the less, even if only a proportion of this reported unfair treatment is true, it is clear that many Australians of sexual diversity are denied equality of opportunity in the workplace.

This phenomenon, together with the educational disadvantage already described, could be expected to have significant adverse consequences for the employment status, income and job categories of homosexually active men. Further, multi-level models remind us that 'vicious circles' of causality can be created whereby a disturbance of mental health consequent on one disadvantage (such as paternal rejection, as discussed) leads to impaired educational and work performance causing social and financial disadvantage that lead to stress that in turn feeds back to worsen the mental health problem.

The analysis and discussion presented in this chapter support the conclusion that at least some (and probably much) of the health inequality experienced by homosexually active South Australian men meets the definition of health *inequity* proposed by Whitehead (see page 39).

# Chapter 8: Sexual behaviour correlates of health inequity

# Introduction

Clearly, the most prominent health inequality experienced by homosexually active men in Australia is their roughly thirty-fold greater rate of HIV infection (see page 244). Although HIV is now a highly treatable infection, it remains incurable, potentially fatal and the treatment for it has its own significant impacts on health and quality of life. Thus, engagement in particular behaviours that may provide the opportunity for HIV transmission is an important health-related characteristic for homosexually active Australian men, much as, say, cigarette smoking is for Australians generally. Because of this importance, and because the factors that determine this characteristic appear to be particularly complex, the correlates of sexual behaviour are explored separately in this chapter.

HIV is not a very communicable virus and is only able to transfer between humans during a limited range of activities. Unprotected penis-vagina (and thus, definitionally, heterosexual) intercourse is overwhelmingly the activity, worldwide, that most often provides the opportunity for the organism to transfer between humans.

There is now little doubt that HIV-1 (the species responsible for most human HIV disease) was first transmitted to humans from chimpanzees in western Africa at least as long ago as the 1950s, probably as a result of hunting and butchering of the primates.(Gao *et al.*, 1999) From there it spread steadily in the indigenous populations of Africa, principally as a concomitant of heterosexual activity. However, the long clinical latency of the conditions it causes, the lack of health infrastructure and the high mortality from other causes in the geographical areas where it first appeared led to a failure of recognition of the organism until a very large proportion of the population was infected.

That AIDS was identified and HIV isolated in the United States and Europe is largely an accident of history. Somewhere in the 1960s or 70s it appears that the virus was introduced, though exactly how remains unclear, into the internationallymobile population of homosexually active white men. From there it entered populations of men who, in the then prevailing atmosphere of sexual liberation, had large numbers of sexual partners, in San Francisco, New York and several European centres.(Kanabus *et al.*, 2005) By the early 1980s the number of these otherwise healthy, young men who had been infected for long enough to have developed serious immune deficiency reached a critical level and 'clusters' of 'cases' of surprising opportunistic diseases were observed by workers in the effective health infrastructures of their countries.

Within three years of the recognition of AIDS among people in the 'developed' world, the virus was 'discovered' by the French, claimed by the United States, and the next year a blood test for its antibodies was available. The 'accidental' appearance of HIV among homosexually active Western men led to the rapid development of scientific and medical knowledge about the disease before it was even recognised to be present in its region of origin. It has only since been understood that the disease has spread widely in Africa and in other 'developing' regions of the world, principally in relation to heterosexual activity.

On the one hand, HIV's sojourn into the First World and its persistence among populations of homosexually active men has led to their being further stigmatised and to a focusing on HIV to the exclusion of the other, serious, health problems that, as has been seen, affect them. On the other, it has resulted in the development of a rapid scientific and technological response to the infection that would have been most unlikely had the virus remained in 'developing' settings, and that may (if the political barriers can be overcome) save countless lives in the Third World.

None the less, HIV remains an important health problem for homosexually active men in South Australia and there have been recent concerns that its incidence may again be rising in this group after more than a decade of steady decline.(Davey *et al.*, 2004)
Because of HIV's restricted transmission repertoire, prevention of the infection has, from its beginnings, been focused on the particular *behaviours* in association with which the virus may transfer from one person to another. Kippax and colleagues have argued that this focus on behaviour has resulted from the science of HIV having been 'colonized from the start by medical discourse'.(Kippax *et al.*, 1993, p

1) They go on to assert that:

[t]he philosophical individualism that underpins much of mainstream medicine and psychology makes 'the individual' or the pieces of 'behaviour' the basic unit of analysis. Combined with abstracted research methods, this produces an *elision of history and social process* ... [that] ... results in categories such as 'behaviour change as an outcome of intervention programs', which effectively deny the agency, and especially the collective agency, of groups who are responding to the epidemic among them.(Kippax *et al.*, 1993, p 4, original emphasis)

This focus on behaviour, posited solely as the consequence of personal volition, abstracted from its context and from the social forces and psychological processes that determine and shape it, has certainly characterised much of the research and prevention practice to date relating to homosexually active men. The recent comments of the current Australian health minister mentioned earlier, augur an even greater emphasis on this orientation in the years ahead (see page 111).

Such an approach may provide some short-term change in the transmission patterns of HIV. As has been argued throughout, however, the determination of human health, and the behaviours that influence it, is actually highly complex. As such, simplistic strategies, perhaps best exemplified by the Australian Government's 'just say no to drugs' approach, (Abbott, 2003) are most unlikely to have lasting benefit.

Notwithstanding all of this, unprotected anal intercourse with an infected partner<sup>\*</sup> is (almost always) a necessary step in the acquisition of HIV by an homosexually active Australian man. HIV has the potential to impact dramatically on health and so it is legitimate to focus on this activity as a health related characteristic.

<sup>&</sup>lt;sup>\*</sup> The 'with an infected partner' component is often overlooked, with an almost magical implication that it is somehow the behaviour rather than the infection that represents the risk to health.

The recent sexual behaviours reported by members of the C&PP cohort were described in detail in Chapter 6 (see page 264). In this chapter, the relationships between having reported behaviours that may have provided an opportunity for further transmission of HIV (either *from* an HIV+ participant or *to* an HIV- one) and the health characteristics discussed in previous chapters will be explored. These behaviours are unprotected anal intercourse with a casual partner (UAI-C) and unprotected anal intercourse with a regular partner who was HIV non-concordant<sup>\*</sup> with the participant (UAI-Rnc). Because insertive and receptive anal sex may have different social, cultural and psychological meanings for some homosexually active men, the two roles were analysed separately, as well as in aggregate in each setting.(Carballo-Diéguez *et al.*, 2004; Hart *et al.*, 2003)

All of the health characteristics listed on page 324 were analysed for association with these activities. The social variables listed on page 325, and the extended sociohistorical measures mentioned on page 347 (for men from whom they had been collected) were also directly compared with the likelihood of reporting UAI-C and UAI-Rnc. All comparisons were made with the report of sexual behaviour in the six months prior to Programme enrolment, except for the comparisons with the Violence and Abuse Score (VAS), which referred specifically to the year before participants underwent Second Review. The VAS was compared with sexual behaviour reported in the six months prior to Second Review.

The statistical techniques described in Table 14 on page 327 were used for these comparisons. For the reasons discussed on page 353, no adjustments have been made in this analysis for the effect of multiple comparisons and this should be borne in mind when interpreting the findings.

<sup>\*</sup> That is, he was either known to have a different HIV status from the participant, or the HIV status of one or both of the men was unknown

# Notes on particular comparisons

#### Age and sexual behaviour

Much of the discourse surrounding the recent apparent rise in new HIV infections among Australian homosexually active men (after more than a decade of declining incidence) has focused on the behaviour of *young* men. As an example, an editorial in *The Age* in Melbourne in 2002 included the following:

There is no cure for AIDS. This reality appears to have eluded some young gay men, whose complacency about the disease is at least in part being blamed for the sharp rise in Victoria's rate of HIV infection over the past two years. ... The increase is heartbreaking, considering the years of research and preventive education that went into making Australian levels of HIV among the lowest in the world. ... The development of drugs that can significantly prolong the lives of those infected means that a new generation of young homosexual men has not had the experience of seeing friends and partners dying in front of them, as many older gay men have. It would be tragic indeed if the safesex lesson had to be learned again in this way.(The Age, 2002, NPN)

This allusion to youth appears to have no basis in fact. The median age of men at HIV diagnosis in Australia has slowly risen from 32 years in 1994 to 36 years in 2003 while the median age of the subset of men diagnosed with newly-acquired HIV has varied between 30 and 34 years during the same period, without a clear pattern.(McDonald, 2004)

In the light of the absence of factual support, it is tempting to conclude that focus on youth in the *Age* editorial might actually have been an example (perhaps unconscious) of a journalist patronising 'naughty gay boys' who were seen as 'ungrateful' for the largess of good heterosexuals, whom they rewarded by behaving 'irresponsibly'.

The findings presented below that there was generally<sup>\*</sup> no relationship between age and the likelihood of participating in UAI-C or UAI-Rnc further refute this position.

<sup>&</sup>lt;sup>\*</sup> The one exception was that men who reported unprotected *receptive* anal intercourse with a casual partner in the prior six months had a mean age of 37.5 years compared with a mean of 41.3 in the remainder of the cohort. This difference was statistically significant, but neither group could really be described as 'young'. Conversely men who reported *insertive* UAI-C were on average slightly older but this difference was not statistically significant.

#### Depressive and anxiety disorders and sexual behaviour

As the author<sup>\*</sup> has reported in the literature, a complex relationship appears to exist among homosexually active men between depressive disorders and HIV risk behaviour (see published paper as Appendix 5 on page 485).(Rogers *et al.*, 2003b)

Previous studies have found conflicting results with regard to the influence of depression on risk taking. Ross (1990), Kelly (1991), Rotherham-Borus (1995), Semple (2000), Strathdee (1998) and Perkins (1993) all found that sexual risk taking was associated with the presence of depressive symptoms in a variety of groups of homosexually active men. Wagner and colleagues, on the other hand, found low levels of sexual activity and sexual risk taking among HIV positive gay men seeking treatment for depression.(Wagner *et al.*, 1993)

Dilley found no association between depression scores and sexual risk taking in a group of homosexually active men attending support groups,(Dilley *et al.*, 1998) and Mayne found that, while recently bereaved gay men were more likely to engage in 'unsafe' sexual practice, depression did not appear to be significantly related to this behaviour.(Mayne *et al.*, 1998) Dolezal, in a recent study of homosexually active Latino men, found a *positive* association between measures of self worth and sexual 'risk taking'(Dolezal *et al.*, 2000), and Robins,(Robins *et al.*, 1994; Robins *et al.*, 1997) found that gay men who reported unprotected anal intercourse had *lower* levels of psychological distress than their peers. Similarly, Rubb's group found that homosexually active men whose responses indicated depressed ideation were *less* likely to report having engaged in receptive or insertive unprotected anal intercourse.(Rubb *et al.*, 1993)

While these results appear conflicting, it seems that no previous study has differentiated between the two common patterns of depression seen clinically, namely MDE and DD, for their effect on sexual behaviour.

On first analysis of the C&PP cohort, no relationship was seen between the likelihood of reporting UAI-C in the prior six months and either depressive disorder or the two depressive disorders in aggregate.

<sup>\*</sup> Together with colleagues.

Among the 161 men with an MDE, 20 (12%) reported UAI-C, compared with 66 (17%) of the 381 men without an MDE (OR = 0.68; 95%CI: 0.395 to 1.160; NS). Similarly, among the 144 men with DD, 28 (19%) reported UAI-C, compared with 58 (16%) of the 398 men without DD (OR = 1.42; 95%CI: 0.860 to 2.328; NS). Among the 204 men with one or other (or both) of the two disorders 33 (16%) reported UAI-C, compared with 53 (16%) of the 338 men with neither disorder (OR = 1.04; 95% CI: 0.646 to 1.667; NS).

But it is recognised that one of the symptoms of *major* depression is reduced libido. Consequently it is no surprise that men with an MDE were less likely to have been homosexually active at all during the period in question, to an extent that approached statistical significance (OR = 0.540; 95%CI: 0.301 to 0.969; P = 0.0542 by FET). Since an MDE may supervene in a person who continues to meet the criteria for DD, this effect could confound any association between DD and unsafe sexual behaviour.



To investigate this phenomenon, the effect on UAI-C of a diagnosis of DD *without* MDE was examined. On this analysis a significant effect was seen. Of the 43 men who met the criteria for DD but not for MDE, 13 (30%) reported UAI-C, while among the remaining 499 men, only 73 (15%) reported having engaged in the behaviour (OR = 2.53; 95%CI: 1.26 to 5.08; P = 0.0144 by FET).



In the light of these results, and the high levels of comorbidity seen (where an MDE complicates other disorders), all of the analyses comparing sexual behaviour and Prime-MD diagnoses have been performed with and without the exclusion of men who also met the criteria for an MDE.

# HIV risk behaviours and health characteristics

In this section the two sexual behaviours most likely to permit further transmission of HIV, should one partner happen to be infected and the other not, are compared with the health characteristics listed on page 324. This analysis considers the effect of existing health conditions, self-rated health status and health-related behaviours (substance use levels) on the likelihood of engaging in these sexual behaviours.

UAI-C is compared with the dichotomous health characteristics in Table 22 on page 367.

Health	Any	UAI-C	Recept	tive UAI-C	Insertiv	e UAI-C
Characteristic	OR	Р	OR	Р	OR	Р
Syphilis Hx	0.877	NS	0.519	NS	0.771	NS
A/gen HSV Hx	2.31	0.0063	2.05	0.0419	2.13	0.0284
A/gen warts Hx	1.74	0.0291	2.27	0.0052	1.60	NS
Gonorrhoea Hx	1.92	0.0077	1.95	0.0221	1.90	0.0251
Chlamydia Hx	4.10	0.0005	3.95	0.0026	3.07	0.0142
NSU Hx	1.74	0.0265	1.97	0.0260	1.79	0.0455
MDE	0.677	NS	0.790	NS	0.656	NS
DD	1.415	NS	1.53	NS	1.28	NS
DD w/out MDE	2.53	0.0144	2.20	(0.0654)	2.05	NS
PD	1.34	NS	2.46	0.0192	0.801	NS
PD w/out MDE	3.35	0.0283	5.84	0.0030	1.199	NS
GAD	1.01	NS	0.899	NS	0.840	NS
GAD w/out MDE	1.18	NS	2.00	NS	0.832	NS

Table 22: Odds ratio of reporting UAI-C in prior six months for men with health characteristic compared with those without. P values by FET. Shaded squares are OR that are significant P < 0.0500. P values between 0.0500 and 0.1000 are included in parentheses for interest. (N = 542, whole cohort)

The most striking feature of these results is perhaps the least surprising. There is a clear relationship between a lifetime history of most of the sexually transmitted infections considered and the likelihood of reporting UAI-C in the prior six months. Since many of the infections are most efficiently transmitted during UAI, the relationship suggests the possibility that the sexual activity reported in the six months before enrolment represents a long term pattern of sexual behaviour that includes UAI-C for a proportion of the men. In contrast, it should be recalled that there was no significant relationship between UAI-C and HIV status (see page 275) which argues against this hypothesis somewhat.

These results also reiterate the relationship already discussed between DD and UAI-C when the confounding effect of men with concurrent MDE is removed. It is of interest that a similar relationship was observed with regard to Panic Disorder, particularly for receptive UAI-C. For Generalised Anxiety Disorder no significant relationship was evident but the odds ratio of 2.00 for the likelihood of reporting receptive UAI-C among men with GAD but no concurrent MDE is consistent with the direction of association for the other two chronic disorders. These conditions that, it will be recalled, are themselves associated with markers of social disadvantage, appear to exhibit a consistent relationship with the likelihood of reporting (especially receptive) UAI-C.

UAI-Rnc is compared with the dichotomous health characteristics in Table 23. In this analysis, only the 126 men who reported any sex with an HIV non-concordant partner have been included, as this seems the most logical way to detect differences between non-concordant couples who do have UAI and those who do not.

Health	ہ UA	Any UAI-Rnc		ceptive I-Rnc	Insertive UAI-Rnc		
Characteristic	OR	Р	OR	Р	OR	Р	
Syphilis Hx	2.81	NS	2.94	NS	1.75	NS	
A/gen HSV Hx	1.54	NS	1.48	NS	1.48	NS	
A/gen warts Hx	1.30	NS	1.43	NS	1.19	NS	
Gonorrhoea Hx	2.15	(0.0840)	3.13	0.0151	1.69	NS	
Chlamydia Hx	5.76	0.0365	9.90	0.0071	1.36	NS	
NSU Hx	1.47	NS	1.15	NS	1.47	NS	
MDE	0.368	(0.0516)	0.375	(0.0965)	0.513	NS	
DD	0.423	NS	0.754	NS	0.371	NS	
DD w/out MDE	2.16	NS	3.23	NS	1.72	NS	
PD	0.880	NS	1.48	NS	0.141	NS	
PD w/out MDE	1.40	NS	2.32	NS	0.285	NS	
GAD	0.811	NS	0.902	NS	0.525	NS	
GAD w/out MDE	6.49 NS		3.43	NS	3.43	NS	

Table 23: Odds ratio of reporting UAI-Rnc in prior six months for men with health characteristic compared with those without. P values by FET. Shaded squares are OR that are significant P < 0.0500. P values between 0.0500 and 0.1000 are included in parentheses for interest. (N = 126 men with non-concordant regular partners)

It can be seen that there are far fewer associations between UAI-Rnc and health characteristics. The direction of the relationship between receptive UAI-Rnc and the chronic psychological conditions is the same as for UAI-C, but no significant associations were observed. This may reflect the smaller sample size but it may also be that the effect of health conditions on sexual behaviour within regular relationships is greatly attenuated by such factors as the health characteristics of the other partner and the dynamics of the interaction between the partners.

The relationships between the sexual behaviours of interest and levels of substance use are reported in Table 24 on page 369.

Health	Any	Receptive	Insertive	Any	Receptive	Insertive
Characteristic	UAI-C	UAI-C	UAI-C	UAI-Rnc	UAI-Rnc	UAI-Rnc
Tobacco use	NS	NS	NS	NS	NS	NS
Alcohol use	NS	NS	NS	(0.0982)	(0.0771)	NS
Cannabis use	NS	0.0427(NEG)	NS	NS	NS	NS
Nitrite use	0.0265	0.0293	(0.0991)	NS	NS	0.0083(NEG)
Amphet. use	NS	(0.0686)	NS	NS	NS	NS
LSD use	NS	NS	NS	NS	NS	NS
Ecstasy use	NS	(0.0964)	NS	NS	NS	NS
Heroin use	NS	NS	NS	NS	NS	NS
Inject. drug use	NS	NS	NS	NS	NS	NS

Table 24: P values for associations between UAI-C/UAI-Rnc and substance use levels. P values by comparison of medians and MWT. Shaded squares are associations that are significant P < 0.0500. 'NEG' indicates a negative association, all others are positive. P values between 0.0500 and 0.1000 are included in parentheses for interest. (N = 542 for UAI-C, N = 126 for UAI-Rnc)

Remarkably few associations are evident in this analysis. The minor negative association between cannabis use levels and receptive UAI-C is most likely a chance finding but it may reflect a generally reduced level of sexual activity in some men who smoke cannabis heavily. The positive association between nitrite use and UAI-C is not a surprising finding. Nitrites are used almost exclusively in the context of sexual activity among gay men and particularly by some to assist with anal relaxation for receptive sex.

The *negative* association between nitrite use and insertive UAI-Rnc is difficult to explain and, despite its impressive P value, most likely represents a chance finding.

The not-quite-significant relationship between alcohol use levels and UAI-Rnc is interesting because it corresponds with clinical anecdotes from several HIV nonconcordant couples in the cohort about having had UAI, where they otherwise wouldn't, under the influence of alcohol (and perhaps of romance) after celebratory occasions such as anniversaries or Valentine's day.

The relationships between the sexual behaviours of interest and scores for sf36 scales are reported in Table 25 on page 370.

Health	Any	Receptive	Insertive	Any	Receptive	Insertive
Characteristic	UAI-C	UAI-C	UAI-C	UAI-Rnc	UAI-Rnc	UAI-Rnc
sf36 Phys. Func.	(0.0589)*	(0.0661)*	(0.0764)*	NS	NS	NS
sf36 Role Phys.	NS	NS	NS	(0.0626)*	NS	NS
sf36 Bodily Pain	NS	NS	NS	NS	NS	NS
sf36 Gen Health	NS	NS	NS	NS	NS	NS
sf36 Vitality	NS	NS	NS	(0.0613)*	(0.0643)*	NS
sf36 Soc. Func.	NS	NS	NS	NS	NS	NS
sf36 Role Emot.	NS	NS	NS	NS	NS	NS
sf36 Ment. HIth	NS	NS	NS	NS	NS	NS

Table 25: P values for association between UAI-C/UAI-Rnc and sf36 scales. P values by comparison of medians and MWT. All associations reported are positive (ie behaviour is associated with *better* self-reported health). P values between 0.0500 and 0.1000 are included in parentheses for interest. (N = 542 for UAI-C, N = 126 for UAI-Rnc)

No significant associations were identified in this analysis. The six near-significant relationships showed a possible association between the behaviours and *higher* levels of physical health or vitality, probably reflecting (if anything) only a generally greater likelihood of having sex when one is physically well or feeling vital.

The absence of an association with the mental health scale does not undermine the conclusions drawn about the chronic psychological conditions above. The sf36 asks about the prior four weeks and thus would be particularly sensitive to the confounding effects of an MDE complicating any of the chronic conditions. Thus a lack of association would be expected if the confounding discussed on page 365 were in action. This is probably true of the other scales at the 'psychological end' of the sf36 also.

What the lack of significant association with sf36 scales underlines is that it is not the general state of a person's health that is related to engaging in 'HIV risk behaviours' but rather the specific conditions identified that, as has been seen, are themselves associated with social disadvantage.

# HIV risk behaviours and social variables

Since reporting UAI-C and UAI-Rnc have been treated as health characteristics in Part 2, it was thought appropriate to investigate them for *direct* relationships with the social and extended sociohistorical variables discussed in the previous chapter. Report of the sexual behaviours of interest on enrolment is compared with the six primary social characteristics in Table 26.

	Any	Receptive	Insertive	Any	Receptive	Insertive
Social variable	UAI-C	UAI-C	UAI-C	UAI-	UAI-Rnc	UAI-Rnc
				Rnc		
Age at enrolment	NS	0.0094 (NEG)	NS	NS	NS	NS
Employment	0.0258(NEG)	(0.0883)(NEG)	NS	NS	NS	NS
Income group	NS	(0.0811)(NEG)	NS	NS	NS	NS
Education level	NS	NS	NS	NS	NS	NS
Occupation type	NS	NS	NS	NS	NS	NS
Lives alone	NS	NS	NS	NS	NS	NS

Table 26: P values for association between UAI-C/UAI-Rnc and social characteristics. Shaded squares are associations that are significant P < 0.0500. 'NEG' indicates a negative association. P values between 0.0500 and 0.1000 are included in parentheses for interest. (N = 542 for UAI-C, N = 126 for UAI-Rnc)

It can be seen that there is a significant association between not being employed and UAI-C, as well as the association between receptive UAI-C and age on which comment was made in the footnote on page 363.

The extended sociohistorical variables described on page 347 were also compared with the UAI-C and UAI-Rnc but no significant associations were observed. The results are presented in Table 27.

Variable	An:	y -C	Recep	otive	Inser	Insertive Any R		Recep	otive Rnc	Insertive		
Vanabio	OR	P	OR	P	OR	P	OR	P	OR	P	OR	P
Emotionally distant father	1.11	NS	1.19	NS	0.688	NS	2.20	NS	3.36	NS	2.73	NS
Emotionally distant mother	0.472	NS	0.742	NS	0.351	NS	0.696	NS	1.22	NS	0.336	NS
Any reported CSA	1.01	NS	0.983	NS	1.18	NS	0.448	NS	0.333	NS	0.727	NS
Non consensual sex as an adult	0.644	NS	0.462	NS	1.210	NS	0.441	NS	0.778	NS	0.235	NS
Violence and abuse score	NS	6	NS	6	NS	6	NS	6	NS	6	NS	6

Table 27: P values (and odds ratios for dichotomous characteristics) for association between UAI-C/UAI-Rnc and extended sociohistorical variables. (N = 210 for UAI-C, N = 58 for UAI-Rnc)

The odds ratios for report of having had an emotionally distant father indicated a possible positive relationship between this report and receptive UAI in both settings but neither reached statistical significance.

It should be borne in mind that the sample sizes in this analysis were much smaller because the extended sociohistorical variables were only asked about at Second Review and only 210 participants had reached this point when the data were analysed. For UAI-Rnc the sample was particularly small (N=58).

# Discussion

Unprotected anal intercourse with a partner whose HIV status is different from one's own is the primary means of transmission of the human immunodeficiency virus between homosexually active men.

In this chapter it has been seen that report of UAI-C<sup>\*</sup>, one of the sexual behaviours where such conditions may<sup>†</sup> be met, is significantly more likely among men who had diagnosable Dysthymic Disorder or Panic Disorder that was not complicated by a Major Depressive Episode on enrolment. Associations with UAI-Rnc were generally in a congruent direction but did not reach statistical significance.

Thus, the chronic disturbances of psychological health that, as has been seen in Chapter 7, are associated with social disadvantage and (for Dysthymic Disorder) with victimisation and abuse, appear to increase the likelihood that homosexually active men in the cohort will engage in UAI-C.

Similarly strong relationships were not observed for UAI-Rnc and this is perhaps because the impact of psychological wellbeing on sexual behaviour between regular partners is moderated by a range of factors including the state of mind of the second partner and the dynamics of the relationship between the two.

Men who reported receptive UAI-C also reported a significantly higher rate of use of inhaled nitrites. Since nitrites are used almost exclusively during sexual activity by gay men, however, this finding is not particularly surprising or informative and should certainly not be taken to imply causality.

<sup>\*</sup> Especially *receptive* UAI-C.

<sup>&</sup>lt;sup>†</sup> They will not always be met. UAI-C, for example, will often occur with a partner who is seroconcordant for HIV, though the respondent will not know this with any certainty. Similarly a proportion of UAI-Rnc will be between partners where the HIV status of one or both is unknown but may actually be concordant.

Men who were employed (by the definition on page 250) were less likely to report recent UAI-C. Men who reported receptive UAI-C were on average slightly (but significantly) younger while men who reported insertive UAI-C were slightly (but not significantly) older. The absence of more extensive direct associations between the sexual behaviours of concern and social factors underlines the complex production of health characteristics and health related behaviours predicted by multilevel models (see page 47).

An occasion of UAI-C is likely to result from the intricate interaction of a wide range of interlocking factors that might include many facets of state of mind, biological factors related to level of libido, the effects of any medications or recreational substances, the availability of partners and their willingness to be involved in UAI, sexual behavioural preferences related to prior sexual experiences and (especially for gay men) prior pornography consumption, attitudes to condoms and the person's sense of power in the interaction (which might itself be related to selfesteem and the degree to which the man wishes to 'please' the partner). Thus it is not at all surprising that relationships that have been observed are themselves subtle and complex.

It is not difficult to understand that gay-identified men who have been stigmatized for much of their lives, and who have lived through the devastation of their community by HIV, may sometimes find themselves in a psychological state where they 'just don't care' about protecting themselves or others. The chronic psychological conditions discussed, and DD in particular, may be the diagnostic representation of such a mental state. Since these conditions may be amenable intervention (as shall be seen) through Primary Health Care they warrant careful consideration in the prevention of HIV at individual and population levels.

# PART FOUR **Counter Measures:** How was a **Primary Health** Care approach applied and what changed in association with its use?

# Chapter 9: Application of a Primary Health Care Approach

# Introduction

Chapter 2 described the origins, history and essential elements of the Primary Health Care approach. Chapter 4 chronicled the history of the establishment of the Care and Prevention Programme to better meet the needs of people living with, and communities affected by, HIV infection, principally homosexually active men. In this chapter the service provided by the Programme (the 'intervention' for the purposes of this study) will be described in detail with reference to the elements of Primary Health Care (see page 66), then in Chapters 10 and 11 the outcomes this 'intervention' will be considered.

When officers of the AIDS Council of South Australia, People Living with HIV/AIDS SA Incorporated and the author conceived the Care and Prevention Project (as it was first called) in 1996, the Declaration of Alma Ata was not in their minds. What the parties brought to the discussions<sup>\*</sup> was a set of shared beliefs concerning: the ability of communities to formulate their own responses to health problems; the value of partnership between affected communities, health providers, scientists and government; the interconnectedness of prevention and care with regard to HIV infection; the importance of the social and the psychological in the determination of health; and the significance of comprehensiveness, multidisciplinarity and continuity as tenets for health care provision.

That these beliefs align closely with the principles of Primary Health Care in the absence of direct reference to them argues for the universality and value of the ideas embodied in the Declaration of Alma Ata. Or perhaps, as a thesis reviewer has suggested, by this time, some eighteen years after the Declaration was made, its values had percolated society sufficiently to have been an unrecognised part of the genesis of the beliefs.

<sup>\*</sup> According to the author's recollection.

Perhaps the best recent operational re-statement of the principles of Alma Ata is the definition of 'progressive Primary Health Care' offered by the (South African) National Progressive Primary Health Care Network (see page 83). These elements will be used as a framework as the operations of the Care and Prevention Programme, the Primary Health Care 'intervention' that is under evaluation, are discussed. They are restated here for convenience:

A progressive primary health care approach:

- 8. challenges the society to address the socio-economic causes of poor health and makes provision for basic health needs
- 9. encourages community empowerment (ensuring that people are fully able to manage resources that are available to them)
- 10. provides comprehensive quality health care including promotive, preventive, curative, rehabilitative and palliative services
- 11. demands concerned and accountable health worker practice
- 12. prioritises the people who are most disadvantaged ensuring that health care is accessible, equitable and affordable to all
- 13. recognises the importance of integrated service provision from primary to tertiary levels of care within a coherent health system promotes inter-disciplinary, multi professional and intersectoral collaborative teamwork for development.(The (South African) National Progressive Primary Health Care Network, 2000)

# The operations of Care & Prevention Programme

The C&PP's core team comprises a 0.7 full-time equivalent (FTE) Programme Director (the author), a 1.0 FTE Nurse Coordinator and a 0.8 FTE Liaison, Policy and Administration Officer. It is co-located with, and cooperates closely with, a general practice that has a particular interest in the health of the Programme's target groups. Since 1998 the practice has employed between two and seven fractional time GPs who have provided medical services to C&PP participants and other patients on a fee for service basis under Australia's universal health insurance system, Medicare.

The activities of the state-funded C&PP and the Medicare-funded medical practice are closely interwoven and appear to be largely indistinguishable from the point of view of participants.

Thus, the 'intervention' for this study is the combination of the functions of the C&PP described in this section and the services provided by the associated practice.

The eligibility criteria for enrolment in the C&PP were described on page 231.

The Care and Prevention Programme has four principle functions, to which a fifth has been added during its life:

- 1. To assess and monitor the health of participants
- 2. To facilitate comprehensive coordinated health care for participants in order to achieve progress toward health goals formulated jointly by the participant, the Programme team and the participant's general practitioner
- 3. To ensure the provision of extended health care services to participants where needed in a manner that is sensitive to their needs and is culturally competent
- To provide educational, personal and professional support to general practitioners and other health care workers who are engaged with the Programme's target groups
- 5. To further scientific knowledge concerning the health of the Programme's target groups and provide expert advice to policy makers based on that knowledge

These functions will be discussed in turn.

#### Health assessment and monitoring

As discussed on page 233, when people who meet the eligibility criteria join the Care and Prevention Programme, after the completion of an informed consent process, they undergo a comprehensive health assessment in the form of on-screen health questionnaires and standardised physical examination by the Nurse Coordinator. Except where otherwise mentioned, the data presented so far are all based on this enrolment assessment.

Subsequently, participants are invited back to complete similar assessments (First Review, Second Review and so forth) at intervals of 18 to 24 months from enrolment. These assessments provide periodic monitoring of progress toward agreed health goals (see below) and provide the opportunity to assess the effectiveness of the Programme for the individual and across all participants.

This function provides information to the individual participant, which assists to empower him (usually) to effect improvement in his health and wellbeing. As such, it contributes to the fulfilment of section 2 in the Progressive PHC definition on page 377. It also provides a baseline against which to determine which elements of section 3 will be appropriate and provides information on participants collectively that allows reflection by workers on the approaches to be employed, thus assisting the fulfilment of section 4. The eligibility criteria that govern enrolment also, to some extent, support section 5 since they select for some of (as has been seen) 'the people who are most disadvantaged' in South Australian society.

#### Care planning, coordination and facilitation

After the initial health assessment, participants in the C&PP are assisted to develop a plan by which to improve their health and wellbeing or modify aspects of their lives, should they chose to, that may improve their future health outlook. This is undertaken by the Nurse Coordinator in close cooperation with the participant and the person's general practitioner. Assistance is then provided to coordinate the components of this agreed plan and facilitate the provision of required services.

This function serves sections 2, 6 and 7 of the PHC definition on page 377.

#### **Provision of extended services**

The C&PP directly provides a range of extended health care services that it would otherwise be difficult for many participants to access. This includes consultation with dieticians who, in addition to general nutritional skills, have particular expertise in the dietary aspects of HIV infection and its treatment; physiotherapy, massage therapy, and clinical psychology consultations.

These services are provided without charge to participants and the service providers have been selected on the basis of an ability to convey sensitivity to and respect for the issues facing homosexually active men as an oppressed group. In addition to the directly funded services, the Programme has also engaged with two specialist medical practitioners (a psychiatrist and a general and colorectal surgeon), who provide consultations to participants at the Programme centre, funded under Medicare. The Programme has encouraged and supported these specialists to develop a professional interest in the health issues of its target groups and expertise in culturally sensitive practice with people of sexual diversity.

During the period under assessment , the C&PP was also able to provide a free dental assessment service to participants through a partnership with the Special Needs service of the Adelaide Dental Hostpital.

The extended service provision function contributes to the fulfilment of sections 3 and 6 of the definition of Progressive PHC and, to the extent that it provides services at no or low charge to people who are financially disadvantaged, of section 5.

#### Health care worker support

This function of the C&PP includes the direct training and mentorship of GPs, GP registrars and medical students in HIV medicine and health care for people of sexual diversity, as well as the provision of educational, professional and personal support to a variety of health care workers (from the C&PP and a range of partner organisations) who are engaged with the target groups. The principal tool for this function is a regular weekly breakfast meeting, facilitated by the Director (the author), where workers can share their experience, discuss issues and gain help and support from other members of the care team. These meetings include reflective discussion of the concerns facing particular participants (with appropriate protection of their privacy) as well as consideration of broader systemic and societal issues, together with sharing of coping strategies for managing the stress of this difficult work.

This function clearly serves section 4 for the Progressive PHC definition by facilitating 'concerned and accountable health worker practice', as well as enhancing quality of service (section 3), integration of care (section 6) and interdisciplinary collaboration (section 7). Further it assists with self-care for the workers and thus might be expected to enhance the sustainability of the whole endeavour.

#### Knowledge development and advice provision.

This function evolved during the life of the Programme as the importance of the information that had originally been collected for evaluation purposes was realised and the team gained increasing expertise and understanding of the issues involved. The contributions made by the C&PP to scientific discourse and health policy development has had a significant impact in terms of 'challenging [South Australian] society to address the socio-economic causes of poor health' among the target groups (section 1) as well as, through advocacy, encouraging community empowerment (section 2).

#### Governance and strategic development

The specific functions alluded to above rest on a foundation of sound governance procedures including a Management Committee that includes two community/participant representatives (one of whom chairs the Committee) as well as regular rounds of consultation with participants and community organisations as the Programme has evolved through its life. These elements support section 2 of the definition of Progressive PHC by encouraging community empowerment as well as enhancing accountability of health workers to the community they serve (section 4).

# Discussion

From this description it can be seen that the Care and Prevention Programme has provided a range of integrated services to participants that meet the criteria for Primary Health Care as articulated in the Declaration of Alma Ata and operational re-statements such as the definition of Progressive PHC by the (South African) National Progressive Primary Health Care Network, (The (South African) National Progressive Primary Health Care Network, 2000) or, for that matter, the recent Adelaide Affirmation (see page 114).

In the next chapter the trajectory of the health characteristics of participants, in association with participation in the C&PP, will be mapped, for the insights it can provide on the Programme's impact.

# Chapter 10: Quantitative measures of outcome

# Assessment of outcome

Participants have been enrolled throughout the life of the Programme and as a consequence there has been 'rolling follow up' with different participants at different points in the review pathway at the time of data analysis. The numbers of participants reviewed to each stage at that time are detailed in Figure 47. Most of the participants listed as 'not yet reviewed' had not been enrolled for long enough to yet be due for the particular review at the time of analysis.



Participants who had undergone a First Review did so a mean of 542 days (~18 months) after enrolment. Those who had a Second Review did so a mean of 1125 days (~36 months) after enrolment. At each review, data were collected utilising the techniques described on page 233.

The outcome data could have been analysed in a variety of ways. One option would have been to include all participants for whom data were present at each time point. These could then have been compared for difference in their mean or median values using unmatched analysis of variance methodology.

This approach would have provided the greatest sample size at each data point but it would have been subject to selection bias if the men who had 'done better', or conversely those whose health has remained the most impaired, had been more likely to have undergone a particular review by the time of analysis.

Thus, for the purposes of the thesis, it was decided to undertake a repeated measures analysis including only the 210 men who had undergone Second Review (that is had completed the first three data points) by the time of analysis (June 30th, 2003). This is expected to eliminate bias resulting from those with the best (or worst) results being overrepresented in follow up, at the price of reduced sample size for the first two data points.

Such an analysis will measure health changes that have occurred in association with *sustained* participation in the Programme since participants who have not engaged closely may be less likely to have responded promptly to requests to return for review and so may have been excluded from the analysis. Thus it may be seen as an upper limit of what can be achieved for people who have engaged most enthusiastically with the intervention. Strategies to promote close engagement are a separate characteristic of Primary Health Care programmes that has not been assessed in this study but obviously bear on the effectiveness of any approach across a whole population.

In a previously published report, these analyses were undertaken using both of the methodologies described.(Rogers *et al.*, 2004) When the approaches were compared, the subset of men who have been fully followed up was found (as might be expected) to have had generally slightly better health at enrolment than the whole cohort (whose enrolment characteristics have been presented in Part 2 & Part 3).

As a consequence less apparent 'improvement' was seen by the repeated measures method (since they started off a little 'better') and so it was seen to be a somewhat 'conservative' analysis for possible benefit, where it was more difficult for statistically significant differences to be confirmed. Otherwise, the two methods yielded broadly similar conclusions and the shapes of the curves were very similar.

As an example, the results for prevalence of Major Depressive Episode at the three timepoints are presented using the two methods in Figure 48 & Figure 49.





It can be seen that, although the starting prevalence was a little lower among men in the repeated measures analysis and thus the P values for change were a little less robust (especially at the First Review data point) no important information about the trajectory of health in association with participation was lost. Thus the more 'conservative' repeated measures analysis will be used for the remainder of this chapter but the considerations above about this being an upper limit for programme effectiveness across a whole population should be borne in mind.

A decision has also been made to present these 'objective' quantitative outcome data in graphical form since this allows the trajectories of the health characteristics to be most easily seen. P values for difference of the mean value or proportion at each Review compared with enrolment were calculated using repeated measures analysis of variance utilising the Instat statistical programme.(GraphPad Software, 1998) Where appropriate, textual discussion accompanies the graphs to illuminate the data and consider the possible meaning of some of the curves.

Although this section of the analysis has been framed as presenting measures of outcome, it must be recalled that since there was no control group, all that can be firmly concluded is that these changes occurred *in association* with participation. No claims can be made to causality and it is certainly possible that other unmeasured factors impacted on the health of participants as well as the C&PP. The issue of causality is addressed to some extent in the next chapter, which presents subjective and qualitative information including why participants *believed* their health had improved.

The first outcome measures to be considered are the eight domains of the short form 36, followed by the overall profiles for these measures of self-rated health, function and quality of life. Since the sf36 derives composite scores from multiple questions, men who failed to complete any of the questions at any time point have been excluded. This leaves 194 men with complete data for repeated measures analysis. Please note that the Y-axis *scale* for all of the sf36 graphs is the same (so that the magnitude of change may be compared) but the x-intercept has been shifted according to the starting values for ease of viewing.

# sf36 scores

#### **Physical Function**



Statistically significant improvement in sf36 Physical Function Score is seen between enrolment and First Review, which is sustained, but does not improve further, between First and Second Review. It should be recognised that some of this apparent effect is likely to represent 'regression to the mean'. This would occur if participants were recruited during a clinical encounter for a condition that had resulted in a temporary impairment of their physical health that was treated or spontaneously resolved.

It may be recalled that in Lin and Ward's study on the use of the sf36 in general practice (see page 312) a significant improvement was seen (only in the Physical Function domain) between sampling one week after recruitment at a clinical encounter (mean score 80.2) and re-testing a further week later (mean score 83.9), and attributed to this phenomenon.(Lin *et al.*, 1998)



#### Role limitation due to physical health ('Role Physical')

This score shows a significant improvement between enrolment and First Review (and average of eighteen months later), which has relapsed to the extent that there is no longer a significant difference from baseline by Second Review (about a further eighteen months later). Perhaps this reflects an initial impetus toward greater engagement in life for participants at the beginning of the Programme that was difficult to sustain over the long term in the face of irremediable physical health limitation for some.



#### **General Health**

Significant sustained improvement in self-assessed general health is seen, in association with participation, between enrolment and First Review. There is then a slight apparent moderation of effect to the Second Review but the final mean score remains significantly higher than the mean among the same men at enrolment.

#### **Bodily Pain**



No significant difference from the mean enrolment scores was seen for this parameter. It should be recalled that in the sf36 a higher score means better health (and thus, in this scale, *less* reported pain).

Although the production of the health experience of pain is complex, in many instances chronic biological dysfunction of a body part due to prior injury or degenerative processes is a significant determinant. It would be surprising if this sort of biological impairment would be greatly affected by a Primary Health Care approach (though the disability it causes might well be, as perhaps is reflected in the Role Physical scale above). Consequently, it is not especially surprising that there has been little improvement in the scale. On the other hand, no deterioration is evident, despite the participants being an average of about three years older by the time of Second Review.

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# Vitality



The pattern for this score resembles that for Role Physical. A substantial improvement is seen at First Review that is somewhat reduced by the Second (to the extent that it loses statistical significance). This might reflect engagement with the Programme producing an early subjective sense of vitality in that was difficult to sustain in the face of irremediable physical health problems for a proportion of participants.

#### **Social Function**



This scale demonstrates the pattern that is seen for all three of the 'more psychosocial' domains of sf36. There is significant improvement to the First Review, and at least sustained benefit with further participation in the Programme.



### Role limitation due to emotional health ('Role Emotional')

As might be expected, the pattern for this score mirrors that of Social Function. There is definite improvement to First Review (implying less perceived limitation on the basis of emotional ill-health) and again there appears from the curve to be some additional, if slow, further benefit from sustained engagement with the Programme.

Both curves could represent a 'treatment effect' from the C&PP, but this cannot be definitively established.

# **Mental Health**



As has been seen with other scores, engagement with the Care and Prevention Programme appears to have been associated with a significant and continuing improvement in self-assessed mental health among homosexually active men in the cohort.
#### **Overall sf36 profile**

In this graphical presentation, the profile of sf36 scores for the reviewed men, at each of the timepoints, is presented, as well as the population norms for South Australian males.



This comparison confirms the impression that men who enrolled in the cohort had somewhat impaired self-assessed physical health (compared with the population norms) and that this impairment has largely resolved since. This most likely represented, to at least some extent, 'regression to the mean' from a state of mild physical impairment that was related to temporary physical conditions that had brought about the clinical encounter at which they were recruited. On the other hand they had marked self-assessed mental health impairment that has also improved, and continues to do so (albeit slowly) in association with participation, but their self-reported health in these domains remains significantly impaired in comparison with the population norms. This second pattern, seen at the 'psychosocial' end of the sf36 'spectrum' is better explained by there having been a definite and continuing benefit in these areas of health resulting from participation in a Primary Health Care programme.

# Depressive disorders

In the next section, the cross-sectional prevalence of DSM-IV disorder diagnoses as identified by the Prime-MD instrument at each time point will be considered using the same graphical methodology.



#### **Major Depressive Episode prevalence**

This analysis shows a marked reduction in the cross-sectional prevalence of Major Depressive Episode, as measured by the Prime-MD instrument, in association with participation in the Care and Prevention Programme. No net relapse and definite continuing benefit is seen with an average of 36 months follow up.



# **Dysthymic Disorder prevalence**

These analyses for the cross-sectional prevalence of Dysthymic Disorder, as measured by the Prime-MD instrument, follow a similar pattern to those for MDE.

Clear improvement has been seen in association with Programme participation, with ongoing benefit evident on extended follow up.

As has been agued, although this cannot be definitively proven in the absence of randomisation and a control group, these data are best explained by a therapeutic effect from engagement with the C&PP that is reflected in a steady improvement in mood and outlook over extended follow up.



# Suicidal ideation

A marked reduction of prevalence of suicidal thought, as measured by the relevant question in Prime-MD, was also seen in association with participation in the Care and Prevention Programme and continuing benefit is apparent on long term follow up.

It should be recognised that despite the best efforts of the Programme team, some men who enrolled are thought to have completed suicide before follow up (see page 316). Any impact of these men not being available for follow up on the measurement of this outcome will be excluded in the repeated measures analysis where all men at each time point are present at the last. To verify this, the analysis was repeated including the six men who had been lost to suicide and assuming that, had they been alive, they would have reported suicidal ideation at follow up. In this analysis (not shown), the prevalence of suicidal thought was a little higher at each time point but neither the shape of the curve nor the P values were different.

# Anxiety disorders

#### **Panic Disorder**



The outcome pattern for Panic Disorder resembles that for the depressive disorders. Although a significant difference is not shown for this lower prevalence disorder, the shape of the curve suggests an effect consistent with the other disorders and the lack of significance may be primarily a function of sample size.



#### **Generalised Anxiety Disorder**

The curve for this disorder differs in an interesting way from those for the other Prime-MD diagnoses. A very dramatic reduction in the prevalence of diagnosable GAD is seen between enrolment and First Review. This effect is then significantly moderated by Second Review, an average of 36 months after enrolment. This may reflect the influence of so-called 'trait anxiety' causing recurrent symptoms and high vulnerability to relapse in some individuals after initial successful management of the 'state anxiety' component of the condition. There does, however, appear to be significant continuing benefit for some participants in extended follow up despite this effect.

# Sexual behaviour with casual partners

Since the middle 1990s in Australia a gentle but persistent rise in the proportion of respondents reporting unprotected anal intercourse with a casual partner (UAI-C) in the prior six months has been noted in almost all behavioural surveys of homosexually active men.(Van de Ven *et al.*, 2003)

In order to compare progress in this characteristic against the prevailing community trend, the following outcome analyses have been superimposed on the rates of this behaviour reported in the 1999 Adelaide Gay Community Periodic Survey (to which reference has already been made and which was roughly contemporaneous with the median date of enrolment in the Programme)(Van de Ven *et al.*, 2000) and in the 2001 Adelaide Gay Community Periodic Survey,(Rawstorne *et al.*, 2002) which was roughly contemporaneous with the median date of enrolment contemporaneous with the median date of all contemporaneous with the median date of all contemporaneous with the median date of all contemporaneous with the median date of second Review.

For interest, a 'whole sample' unmatched analysis has been included as well as the repeated measures methodology because on this one characteristic there was an important difference between the men who had been reviewed and those who had not to the point of analysis.

As can be seen in the figures on page 404, the 210 men in the repeated measures analysis reported a rate of UAI-C at enrolment that was identical to the rate among men in the 1999 Periodic, while the rate in the whole enrolled cohort was somewhat (though not significantly) higher.



It can be seen from these analyses that there was a fall in the rate of report of recent UAI-C between enrolment and First Review that was significant among all men reviewed but did not reach statistical significance on repeated measures analysis in the smaller group who have been reviewed to the third data point.

By Second Review some of this reduction had relapsed and indeed the repeated measures cohort was back to the enrolment rate.

These measures were made, however, against a complex national behavioural trend toward an increasing rate of UAI-C. In this setting the relevant question may not be whether a sustained absolute reduction was achieved but rather whether participation in the Programme was associated with rates that were significantly different from those seen in other contemporaneous studies.

By this analysis, participation in the Care and Prevention Programme appears to have been associated with significant attenuation of the trend towards an increase in UAI-C that has been seen around Australia. Among the 542 men who enrolled in the C&PP cohort, the rate of UAI-C reported was numerically (though not significantly) *higher* on enrolment than the rate in the 1999 Adelaide Periodic Survey. A median of 36 months later, the rate of UAI-C of 11.6% among Programme participants reviewed was significantly lower than that in the corresponding community survey. Participants had an odds ratio of 0.554 (95%CI: 0.364 to 0.842; P = 0.0054 by FET) of reporting UAI-C in the prior six months compared with the 565 men in the roughly contemporaneous 2001 Periodic Survey.

## HIV non-concordant UAI-R

As was identified earlier, unprotected anal intercourse is common between regular sexual partners (UAI-R) but only a proportion of this sexual activity represents a material risk for further HIV transmission.

UAI-R where the participant knows his regular partner to be of different HIV status or where the HIV status of either party is unknown (HIV non-concordant UAI-R or UAI-Rnc) does pose a significant risk of HIV transmission however, and was reported at a concerning rate among members of the cohort on enrolment (see page 269).

In contrast to the outcomes described for UAI-C, participation in the Programme appears to have been associated with little change in the rate of this behaviour.

The analysis below shows no significant difference in report of UAI-Rnc among all men who had sex with regular partners.

In the subgroup with the greatest level of risk (men with regular partners whom they know to be HIV discordant) a small effect only was seen at the First Review, but this had attenuated below statistical significance at Second Review. Repeated measures analysis was not undertaken for this measure due to small sample size.





Clearly, sexual behaviour that occurs in the context of regular relationships will have elements in its determination that are less amenable to modification through a Primary Health Care programme, such as the state of mind of the other partner and the dynamics of the relationship.

#### Substance use

Questions on substance use levels were not asked at First Review and so comparison can only be undertaken between Enrolment and Second Review. As with the other parameters presented so far, progress in these characteristics has been analysed by comparing each participant's use level at Second Review with his own level at enrolment. This paired analysis eliminates bias resulting from a selection effect if people with worse (or better) outcomes were more or less likely to have been reviewed by the analysis date. Conversely, it demonstrates the effect that has been observed in the most closely engaged portion of initial enrolees and thus may represent an upper limit on the effectiveness of the programme across a whole population. The reasons for analysing outcomes in these two ways are discussed at the beginning of the outcomes section on page 386.

For all of these analyses, mean levels of use are compared graphically but the statistical analyses conducted compared medians by non-parametric methods (Willcoxon Matched Pairs Signed Ranks Test) since the scales of substance use are ordinal rather than interval in nature.

The usage scales to which the graphs refer are presented in Appendix 2 on page 477. Please note that the nominal alcohol use scale was re-coded as specified in the appendix into an ordinal scale.

Two men failed to complete the drug use instrument at Second review and have been excluded, leaving 208 men on whose data the repeated measures analysis was performed.

#### Tobacco use



Given the high levels of tobacco use in the cohort on enrolment it is pleasing to see a small but significant change by paired analysis among reviewed men. In addition to the general Primary Health Care measures described on page 378, the C&PP team collaborated with Gay Men's Health at The AIDS Council of SA and Quit SA on a specific programme to study and address this health behaviour and it appears that some benefit may have resulted. It should, of course, be recognised that tobacco use rates are falling among Australian males generally over time and it is impossible to determine the extent to which the specific programme influenced this characteristic.

#### Alcohol use



As can be seen from these analyses, there has been little impact on alcohol consumption associated with participation in the Programme. The paired analysis shows a possible reduction that approaches statistical significance but at any rate is small in magnitude, especially given the higher levels of use in the cohort at enrolment compared with men in the general community.

Alcohol appears to be a central cultural feature in the lives of many gay-identified men and may prove quite difficult to influence through health promotion.

It will be an important target for the Programme in the future, particularly in light of the possible association with UAI-Rnc identified on page 369, and the, albeit limited, benefit seen from brief interventions for alcohol use in the Australian general practice setting. (Richmond, 1995)

#### **Cannabis use**



As the enrolment data showed (page 303), cannabis use is extremely common among homosexually active men. It may be that it is used, at least in part, as a buffer against the emotional effects of lifelong discrimination and victimisation.

In recent times, however, considerable evidence has emerged about the health consequences of the substance,(Hall *et al.*, 1998) and so cannabis use represents a continuing challenge for Primary Health Care with gay-identifying men.

As the analyses above demonstrate, participation in the Programme appears to have been associated with no significant change in patterns of cannabis use.

#### Nitrate use



The inhalation of nitrite 'poppers' is, as the enrolment data confirm (page 304), common among homosexually active men but it is quite unusual outside of this community. It serves as an example of the connections between drug use patterns, social context and cultural mores. It is also an activity with very significant health risks and, as has been shown (page 369), a significant association with sexual risk-taking with casual partners. Consequently, it is pleasing in health promotion terms that a significant reduction in the level of use was seen by paired analysis among men who had returned for Second Review.

An interesting development that may bear on this pattern of change is the increasing use of sildenafil ('Viagra') and related agents for erectile dysfunction observed clinically among homosexually active men. Nitrites are particularly dangerous in combination with these agents and Programme team members worked hard to ensure that participants are aware of these dangers.

## Amphetamine use



Amphetamine use has been common in Australia for some years and, as the enrolment data comparisons show (page 305), appears to be considerably more frequent among homosexually active men.

Much has been made recently of the impact of amphetamines (particularly in the form of 'crystal meth') on sexual behaviour among homosexually active men.(Ross, 2004) It has been suggested that the increased use of the drug has had a causative effect in the rise in new HIV infections in the United States and some Australian jurisdictions. Others have argued that the relationship between the drug and sexual behaviour is much more complex.(Slavin, 2004) In the C&PP enrolment data a near-significant association was seen between amphetamine use and report of *receptive* UAI-C (page 369). The agent's negative effect on erectile function may account for it not showing any association with insertive UAI-C.

The analysis above shows little impact on the use of this substance in association with Programme participation. To the extent that the drugs are related to HIV risktaking, health promotion concerning amphetamine use remains a challenge for the future.



#### LSD and related substance use

These data accord with the author's clinical observation that the 'cardboard trip' is an example of a drug that may be going out of fashion among homosexually active men.

As the enrolment data show (page 306), cohort members are much more likely to have *ever* used this drug than men in the general community, but are probably not much more likely to have used it in the year before enrolment.

As such, the significant reduction in use level seen above may simply reflect the time effect of a reduction in use that preceded enrolment in the Programme, since the use scales incorporate both frequency and recency of use.



#### **Ecstasy use**

Recent use of ecstasy was roughly three times more common among men in the cohort at enrolment than among men in the general Australian community (see page 307). In all but three participants, however, the reported rate of use was 'occasional' or less.

No change in rate of use appeared to be associated with Programme participation. No incidents of serious medical consequences, so avidly reported by the media, were seen in the cohort, however, between enrolment and review.

#### Heroin use



Unlike most of the drugs we have studied, the rate of recent use of heroin does not appear to be particularly greater among homosexually active men than men in the general community, although a higher proportion have used at some stage (see page 308).

The paired analysis suggests a significant, if subtle, reduction in heroin use level in association with participation in the Care and Prevention Programme, though it should be realised that this was also contemporaneous with a reduction of heroin supply in Australia.

# Injecting use of any drug



No significant change in the rate of injecting drug use was seen in the paired analysis but the level of use among these men was already very close to 1 ('Never used') and so significant further reduction may be difficult to identify.

## New diagnosis of HIV infection

Three men in the cohort were diagnosed HIV+ for the first time between enrolment and First Review.

None of these had a documented seroconversion whilst participating but all three reported having tested HIV negative at some point prior to enrolment.

One had tested HIV antibody negative one week prior to joining the Programme and was diagnosed HIV+ eighteen months after enrolment. Even accounting for the window period for the HIV test (an average of about 4 weeks with the tests in use at this time), it appears very likely that he was infected whilst enrolled.

The second reported having tested HIV- three years prior to enrolment. He believed himself to be HIV+ on enrolment, on the basis of repeated UAI with a positive regular partner, but felt emotionally unready to be tested at that time. He did not recall a symptomatic primary infection. The participant tested HIV+ six months after enrolling. He was probably infected before he joined the Programme but based on timing alone, he has a one in seven (0.14) chance of having been infected whilst he was a participant (six months in the Programme out of a total of 3.5 years between last negative test and diagnosis).

The third had tested HIV- nine months before enrolment. He was diagnosed HIV+ on routine testing six months after joining the Programme. In pre-test counselling he recalled risk behaviour and the likely symptoms of a primary HIV infection at about the time of his last negative test, and was probably infected around this time. Again, it seems unlikely that he was infected whilst participating in the Programme, but based on the timing of testing alone there is a 6/15 = 0.4 chance that he was infected after enrolment.

No further new HIV infections were identified at Second Review.

Thus the estimated equivalent number of people diagnosed with HIV infection acquired after enrolment is 1 + 0.14 + 0.4 = 1.54 out of 284 initially HIV-/? men who were still alive and with whom the Programme team was still in touch at 30/6/2003, a mean of 1374 days after enrolment (1068 person-years of follow up). This yields an annual new diagnosis rate for the cohort of 1.1 per thousand.

73% of HIV-/? men reviewed and 47% of all HIV-/? men enrolled had been retested at some stage since enrolment.

As a comparison, among homosexually active men aged 25 years or older seen at Australian metropolitan sexual health clinics, the rate of new infections increased from 10.5 per thousand in 2000 to 36 per thousand in 2002.(McDonald, 2003) In the Health in Men (HIM) cohort study among homosexually active men in Sydney, 4 cases of newly acquired HIV infection were diagnosed in 2002 among 392 men who were HIV seronegative at enrolment in 2001, giving an annual incidence of 9.8 per thousand.(McDonald, 2003).

The rate in the HIM study is almost ten times that among C&PP participants, and the rate for men aged 25 and over at metropolitan sexual health clinics is now more than 30 times that seen in the cohort. Even accounting for possible incomplete ascertainment, the rate of new infection in the cohort does appear to be much lower than the comparison rates.

Since the analysis at 30/6/2003, the Programme team has become aware of two men who were diagnosed with HIV infection among the 41 men who had left the Programme to move interstate. One had tested HIV- while participating in the Programme, before his departure, and the other tested HIV- just before he enrolled. If these men had *not* been lost from the Programme but had still become infected this would raise the rate to 3.54/286 men, yielding an annual diagnosis rate of 3.2 per thousand. This is still less than a third of the rate in the HIM cohort and a tenth of the rate among homosexually active men attending sexual health clinics in 2002.

The fact that these two new infections occurred among the 41 men who had not been in contact with the Programme due to being interstate is interesting. If two is taken to be the minimum number infected among this group, (assuming that none of the other men who have moved interstate have been diagnosed or infected) this yields a minimum rate of 2 out of 156 person-years or an annual incidence of 13 per thousand among men who have left the Programme to move interstate.

If the rate among men still participating is rounded to a whole number, comparison can be made between the number of person-years in which a new infection was or was not diagnosed in the two groups by a 2x2 table.

As discussed above, it appears most likely that only one new infection has been detected that was acquired while the participant was enrolled in the Care and Prevention Programme. If this were true, then one out of an estimated 1068 person-years of surveillance of the participating cohort has resulted in an infection, yielding an annual incidence of 0.94 per thousand.

In this scenario, a person-year of follow up for men who left the cohort to move interstate would have had an odds ratio of 13.9 (95%CI: 1.25 to 154; P = 0.0444 by FET) for having resulted in infection compared to a person-year of follow up for men who remained in the cohort.

Even if two new infections actually occurred among men enrolled at the time (annual incidence of 1.9 per thousand) the difference by  $2x^2$  table would still approach statistical significance (OR= 6.92; 95%CI: 0.968 to 49.5; P = 0.0814 by FET). If all three men diagnosed were actually infected while participating, the difference would not be significant. On the other hand, if more men than the two identified have been infected among those who have moved, the magnitude of difference from the cohort would be greater than in the examples.

Many assumptions are made in these discussions, and the numbers remain small. On balance, however, it does seem that participants who have remained in touch with the Programme have rates of new infection that are substantially lower than either men in the Sydney HIM study or men homosexually active men seen at Australian metropolitan sexual health clinics.

Further, men who have remained engaged with the Programme may have been less likely to have had a new diagnosis of HIV infection than men who have left the Programme to move interstate.

# Discussion

Clearly the Care and Prevention Programme was not able to prevent all negative health outcomes in the cohort of homosexually active men with whom it was engaged.

As documented in Part 2 (see page 313), sixteen men died to June 30<sup>th</sup>, 2003, and it is likely that six of these suicided. Each of these outcomes is to be deeply regretted. Each death was reflected on closely by the Programme team and a little was learned from each that might help to prevent further such tragedies among South Australian homosexually active men in the future.

Further, at least one participant (and possible up to three) was newly infected with HIV whilst enrolled in the Programme.

The data presented in this chapter, however, suggest that many other negative health outcomes may have been prevented (there was a fall in suicidal ideation rate and the rate of HIV seroconversion appears to have been below that seen in comparable populations). Many aspects of the health of participants has improved, on average, in association with involvement in the Programme.

In the next chapter, participants' subjective satisfaction with the Programme will be assessed and, through a qualitative research methodology, their beliefs about why their health has improved will be explored.

# Chapter 11: Subjective and qualitative measures of outcome

In addition to the more 'objective' measures of 'outcome' documented in Chapter 10, two other methods have been employed in an attempt to determine quality and effectiveness by the Care and Prevention Programme.

The first is a process of quantitative (but, definitionally, subjective) satisfaction rating by participants at each review, augmented and clarified by the solicitation of free text comments that can be subjected to analysis by qualitative methods. The second is the practice of critical reflection and organisational learning undertaken by the Programme team, as advocated by Legge and colleagues (see page 98) as a solution to the problem of externalised 'outcomes' in Primary Health Care.

# Satisfaction rating and free text commentary

At each of the review points, participants in the Care and Prevention Programme were asked to rate their satisfaction with each service they had used and with the Programme overall. A five point Likert-type scale ranging from 'completely satisfied' to 'highly unsatisfied' was used for each rating. For this section of each Review, participants were particularly encouraged to enter their comments directly into the database in the absence of any members of the Programme team. This was intended to minimise bias resulting from reticence to offer criticism if team members were present. The few participants who were unable to enter data without assistance were offered the option of having their data entered by a different team member. Respondents were also asked for free text comments on each service and for narrative information on any problems they had encountered with the Programme, together with any suggestions they had for improvement.

A numerical summary of participants' overall satisfaction with the Programme will be presented first. Then, for each service, quantitative information on participant satisfaction will be presented together with an analysis of the free text comments. All available quantitative data for each time point were included. The qualitative investigation was undertaken without the use of qualitative analysis software,

utilising the standard techniques of thematic analysis.(Corbin *et al.*, 1990) This involved the author alone reading all free text comments on each service then the identification and elaboration of common themes in the responses. No formal rechecking of the qualitative conclusions with respondents was undertaken, but a report that included them was distributed to participants. The small amount of spontaneous feedback received after this distribution indicated accord with the conclusions.

Identified themes are presented textually, with illustrative quotations.

Finally, participants' accounts of problems with the Programme and suggestions for improvement will be summarised using the same qualitative techniques.



#### Satisfaction with the Programme overall

Participants reviewed indicated extraordinarily high levels of satisfaction with the Programme overall. The majority of participants described themselves as 'completely satisfied' at both time points, very few expressed any level of dissatisfaction, and no participant at either review chose the 'highly dissatisfied' response with regard to the Programme in general.



#### Care coordination and nursing service

Levels of satisfaction with this service were very high indeed. Participants appear to have had a clear idea of the coordinator's role and their comments almost uniformly indicate that the service met their needs.

As one participant put it:

I found [the Nurse Coordinator (NC)] to be of great assistance to me when I joined the program last year. His genuine concern for my well being and attention to detail was simply fantastic. At a very down period in my life, he was the one who really gave me the boost I need[ed] to pull out of it. His follow up on my progress is much valued and I have enjoyed liaising with him over the past year. He is truly an asset to this organisation.

And another:

I feel very comfortable with [the NC]. He makes the process pleasant and he is very inclusive. I feel that we both are involved in my health rather than just being told.

Elements of the Primary Health Care approach were appreciated by others:

I enjoyed the totally ... relaxed environment, especially the honesty. I received information which was important to me and [was] able to get ... information and knowledge. I will not hesitate to ring [the NC] in future for anything or any matter concerning myself, my health and my emotions.

I have learned a lot about living my gay life because of [the NC]. He has given me good resources for personal growth, for example he has given me contact resources for Hep C. I have also found that [the NC]'s open door way of working has been good for me.

[The NC] has helped me with my problems with housing in the past year.

The liaison component of the role was also appreciated:

...it has been vital for me to have [the NC] so accessible. From time to time I have rung [the NC] for one thing or another, and [he] has been able to answer the questions there and then, or has got back to me. This has been good when it is often difficult to speak with the doctor. I also believe this is vital for the HIV community to have this accessibility.

Remarkably, only two comments displayed any degree of dissatisfaction. One voiced concerns about the means of contact with the participant. The other sought more intensive support and coaching:

I enrolled in the program with an expectation that [the NC's] role would be to assist me to structure a program of health and fitness reclamation ... I am actually looking for a regular overview of my health and fitness, with an opportunity to talk through how each of the areas might be going, with an opportunity to change emphasis. It's also partly about wanting to have someone other than me who can say "You need to be doing more or less of ..., I think you need to do ...". Say once every two - six months.



#### **Dietetic and nutrition service**

Participant satisfaction with the nutrition service was also generally high. Many participants commented positively on the information received:

A very well spent hour - I learned a lot about my present diet and went away with increased confidence about how and what I should eat.

It all makes such sense and is not painful.

[The dietician] *provided me with a lot of information and answered questions in great depth that I asked.* 

And the results of interventions:

They gave me advice regarding my fat intake which seems to have corrected the diarrhoea I was experiencing.

I got the results I wanted. Her suggestions really did work for me in gaining weight.

I received clear information. It was a diet programme I felt I could stick to. It did result in a marked improvement with regard to my irritable bowel.

Many participants appreciated help with antiviral drug side effects:

The dieticians provided very valuable assistance in helping to alleviate the symptoms of combination therapy. They were also wonderful for assisting with the maintenance of a desirable body weight and image.

Seemingly conflicting comments were made about the materials provided:

I would have liked to have received some more information ie a brochure which was easy to read regarding a greater variety of foods to take with my tablets. It would have been nice to have received some recipes and been [offered] reference books rather than the one page sheet I was given.

[The dietician was] ... extremely helpful in providing copies of printed information to take home for reference and providing sample diets, etc.

The few negative comments referred either to conflict with other advice, consulting style or lack of commitment on behalf of the participant:

I felt that what they were advising sounded faddish ... Her views were opposite to what I had believed to be right.

The quality of the consultation was fine, however my personal commitment was inadequate.



#### **Physiotherapy service**

Four different physiotherapists were involved in the C&PP to June 30<sup>th</sup>, 2003, and participants have had differing opinions about the styles of each. This service has never received government funding but has been provided through pharmaceutical sponsorship. Many participants have found it valuable for the management of symptoms such as HIV associated neuropathy and recovery from serious health events:

He gave me a piece of equipment (TENS) for pain relief which I found effective and I found him very knowledgeable and helpful for ongoing exercise.

I feel that it is vital for some positive people to be able to access these services and much needed part of the project.

*I thought* [a particular physio] *was very helpful with advice for my recent stroke. He also gave me information on meditation.* 

Participants valued educative aspects of physiotherapy:

*I found* [a particular physio] *explained the existing problem in an easy manner which helped me to understand the problem better. And how best to alleviate the existing pain.* 

They have not only treated me as a valued client, but have also given me very helpful exercises, both for posture and for neck problems, to practice at home.

The clinical style of one of the therapists was thought by some participants not to accord with the overall approach of the Programme:

He didn't bother to take a history or pay any attention to the larger aspects of my life ie a holistic approach.

But most of the negative comments related to the limited availability of the service related to a shortage of funding:

I tried to get in to see the Physio for an acute neck problem, but was informed that they were booked solid.

Could not make use of service due to over bookings and availability.

... it can be difficult to get in to see him. So please get him more often and during the daytime as well especially in the winter.



#### Massage therapy service

Three massage therapists have provided services in the Programme since it began, again funded from commercial sponsorship and the generosity of practitioners who either volunteered or accepted very low fees. This service seems to have been very appreciatively received:

I think this service is fantastic and I have benefited ten fold from having a massage.

#### Wonderful

I think this service is one of the huge plusses of the whole Programme, in as much that men who carry mental and physical distress can be very professionally relaxed. I found this service satisfying and have left feeling so much better than when I entered

Both [massage therapists] are vital to assist maximising one's ability to stay well.

The therapeutic benefits are many and much appreciated.

A few participants found that the massage techniques of particular therapists did not agree with them:

I felt that it was too brief and that he didn't hit the right spot.

I felt somewhat uncomfortable with him.

But the free text comments suggest that the majority of dissatisfaction in the quantitative analysis relates to difficulty in obtaining an appointment, again related to shortage of funding for the service:

*Excellent program. There should be more masseurs for the amount of people on the program.* 

I can never get in. Whenever I ring for an appointment I am told that the waiting time is whatever, and I give up.

I felt this was a welcome addition to the project and looked forward to massage but he only has one pair of hands and it is difficult to get an appointment.

*I ... found him very professional. Totally relaxing. Sadly, he is so booked up that I have been unable to get back again.* 



#### **Dental assessment service**

Dentists and dental nurses from the Special Needs Unit at the South Australian Dental Service (SADS) provided a monthly assessment service at the C&PP headquarters that appears to have been greatly appreciated by participants. Concerns about oral health and oro-genital transmission of HIV are very real for homosexually active men and this initiative provided access for men who might not otherwise have been able to obtain timely dental advice. Follow up was provided through SADS or referral to private dentists as appropriate.

Most comments were appreciative of the service:

[The dentist] *was very professional in* [their] *manner and* [the dentist's] *information was clear and gave me alternatives.* 

I found the dentist very helpful and fun as I have been very frightened of dentists.

I have found the service provided ... totally satisfactory and very informative.

Some participants commented on the appropriateness of dental assessment in the Programme:

The dental hospital involvement in the project provides a wonderful opportunity for these two branches of my health care to share information and provide a more complete service.

The few negative comments related to conflicting advice received from other dentists, issues of 'HIV sensitivity' and concern that free dental treatment (as opposed to assessment) was not available to some men through SADS:

Within a few months of [dental assessment I was told that] I required three fillings, which I feel the dentist concerned should (could) have noticed and advised me of the necessary work.

Perhaps due to my oversensitivity at the time, [the dentist] unintentionally phrased a comment poorly. The comment related to wisdom teeth, HIV and implied inevitable illness. This did sadly impact negatively on my well-being for about a week later.

*My (HIV negative) partner however feels very let down by his lack of dental care which he was lead to believe he was able to access at the dental clinic.* 

Dental care should be still available to participants of the programme who are hep c positive, but do not have a healthcare card (ie are in the workforce)




The general practitioner service provided in association with the Programme by O'Brien Street Practice was very positively rated by participants:

[My GP] is the best doctor I have ever had, in that [the GP's] manner is friendly and relaxed yet completely professional. I feel that my understanding of my personal health issues have improved substantially since seeing [them].

I am constantly amazed at the quality of the service provided by [the GPs]. My friends just cannot believe that GPs would provide such a comprehensive service that considered the health of the whole person, not just treated physical symptoms.

*I have had excellent medical services at this Practice since moving to SA from* [another state]. *I have been made to feel "like gold".* 

Professional attitude. Levity to overcome my embarrassment. I feel comfortable and confident in [the GP's] care. [The GP] gives me full detailed information, doesn't hold things back [and] gives me full emotional and spiritual support when I have needed it.

Comfort with and acceptance of gay-related issues was seen as critical:

I always feel comfortable coming here as I also find [my GP] to put me at ease. [My GP] is the first doctor... that I could speak openly and freely with about any issues, especially gay issues.

I think that being gay/gay sympathetic has made all the difference

The reason I come here is that there are gay friendly GPs here.

I would like to say that being normally a person who finds it difficult to trust doctors ... I have found for the first time in my life a situation where I feel comfortable, accepted, and totally trusting with every member of the O'Brien Street Practice.

More recently, however, the nationwide shortage of GPs, and especially GPs willing to work in this area has affected service availability significantly and this has been reflected in some participant comments:

Unless I have two or three days to wait I can never get in to see the doctor of my choice on the same day. I have never experienced this with any GP that I have had before.

The doctors do seem a little rushed, more so than they used to be. This is a shame because I would like to spend more time with them when I see them. Also, I have found bookings to be tight.

#### **Psychiatry service**



Since the C&PP began, a regular consulting service has been provided by a private psychiatrist who has developed an interest in the health of the target groups.

In addition, the psychiatrist has provided clinical advice to the GPs who have provided primary mental health care to most participants.

While high level dissatisfaction was uncommon, the wide spread of satisfaction ratings in the quantitative assessment may reflect the psychiatric process where patient discomfort is sometimes induced purposefully.

The majority of free text comments were very positive, with the issue of sensitivity to sexual diversity seen as particularly important:

[The psychiatrist was] very sympathetic, knowledgeable about nonheterosexual concerns. Has assisted me in looking at aspects of myself and explaining the situation occurring with my partner.

I am very satisfied with him. He has been very helpful. This is one of the reasons why I am feeling so positive of late.

[The psychiatrist has] been most helpful. He has probed the sources of my depression very deeply and been very flexible and available during very difficult times for me. He has also dealt with practical day to day issues about life skills and basic survival under times of extreme pressure and depression for me. Medication has been useful in conjunction with counselling.

*I am very happy with* [the psychiatrist]. *He has helped me tremendously in a short space of time. I find him friendly & warm but he still maintains a highly professional standard.* 

There were positive and negative comments on the professional approaches employed:

I found him easy to talk to as he had the ability to draw responses from me. I don't like Psychiatrists who simply leave you [to] do all the talking.

I found him useless. He didn't really help me; all he wanted to do was to put me on to drugs.

He is a good listener and has given me good keys to help.

I did not feel any bond between us. I felt like I was talking with my teacher.

Several participants were also concerned about tightness of access:

He is very difficult to get an appointment with, especially when I need him.

*I wish that* [the psychiatrist] *could have longer consultation times, or more frequent sessions.* 



# General and colorectal surgical service

Access to surgical services in an environment that is gay-comfortable and 'unfazed' by HIV infection has long been a difficulty for GPs working in this area and their patients. Two private surgeons have provided such a service since the Programme began, with monthly consultation and minor procedures at the O'Brien Street centre, and liaison with the public and private hospital systems to facilitate sensitive day-surgery or in-patient care where required.

The majority of participant comments were positive and perhaps a little surprised at the non-discriminatory approach:

[One of the surgeons] *has operated twice on me and I have seen him here as well. I find him tactful and professional.* 

[The surgeon] *did my hernia operation earlier this year. Indeed, my whole experience at* [a particular public hospital] *was very good, very professional.* 

[The surgeon] *operated on me last year and will need to do another soon. I find him very nice approachable person. He put me at ease when I went into* [a particular public hospital] *last year.* 

*I have seen* [one of the surgeons] *for my operation on my bowel. Very satisfied with both what he did and the way he goes about it.* 

I saw [one of the surgeons] and find him to be great.

The few negative comments related to perceptions of consulting style or a desire for even greater knowledge of gay-specific issues.

*I think that* [one of the surgeons] *needs a course in interpersonal communication.* 

I have problems with my bottom and was hoping that [the surgeon] could fix it. But when I saw him today he said that there was nothing he could do for me as he said he couldn't see anything ... This is frustrating for me because this has been a problem for the past six months and my sexual life is restricted due to this.

He was ignorant about the sexual functioning of the anus and told me so. I wonder what he is doing here??? This issue is of long-standing for me and I was looking for some decent medical guidance. However, at the same time, he did give me some information and that was sort of useful, but did not assist me in any way in me feeling like there was a comfortable and effective way to enjoy anal sex better.

#### Problems encountered with the C&PP

Apart from difficulty in getting appointments with services that had limited availability and requests for services not currently provided, remarkably few participants identified problems in their dealings with the Programme:

Only the limitations of the amount of sessions that are available for the various services.

No problems other than my efforts to get appointments with the popular services. This is an example of the obvious success of the Programme.

More time with the masseur would be good. Once every six weeks is not beneficial enough. I also think you need a podiatrist as part of your services. A lot of HIV patients have feet trouble and have trouble getting down to their feet.

Mainly the time it takes to get an appointment.

There have been times when I have [been] frustrated with not being able to get in for appointments due to heavy demand on these services. Others have made the same comments.

One participant had concerns about:

Parking.

But another observed that the centre was:

... well accessible for parking.

Another had concerns about the use of antiseptics in the building leading to his being:

not happy with the indoor air quality ... due to my multiple chemical sensitivity.

Others took the opportunity to express concern about gap fees charged (at the time<sup>\*</sup>) for medical services by the associated general practice:

I object to a Surgery that does not have the option of bulk-billing for people on very low incomes

Several participants at First Review suggested a periodic newsletter to inform participants about developments in the Programme and remind them about the services available. This suggestion was taken up and the results were appreciated by *participants at later review:* 

The very good thing that you have begun to do is sending out Newsletters. This has been good to receive as it keeps me up to date with any changes and your findings. As I feel somewhat isolated in the gay community, this often is my only channel for learning about different issues.

Increasingly, in recent times, participants have commented on difficulty obtaining appointments with particular GPs or occasionally with a GP at all in the associated practice. This reflects the crisis in GP availability and difficulty in attracting and retaining clinicians in this area of work, despite the specific support strategies discussed on page 381:

Access to GP's becoming more problematic.

I am pissed off that [my GP] is leaving.

The only problem I have had is that when I am sick I often cannot get an appointment to see ... my doctor. I do know that I could see someone else, but I would prefer to see [my GP]. Consequently, days pass before I can get in.

*Too many people rely on* [my GP] *and this places* [the doctor] *under great pressure.* 

<sup>&</sup>lt;sup>\*</sup> O'Brien Street Practice has since responded to this criticism by offering bulk billing for Commonwealth Health Care Card holders.

#### Suggestions and comments

At each review participants were asked to make suggestions for improvement of the Programme. Relatively few did so and indeed many identified that this is a result of their high levels of satisfaction:

*I* can't think of a single suggestion about how you can improve the Programme. I just think that the Programme [is] a good idea.

I am happy with the Programme as it is.

The Programme as such is fine I can't think of anything to say

*I don't think there is anything I can suggest about ways to improve* [the] *Programme.* 

I have a large network of friends who, like myself, speak highly of this clinic and Programme. We all think that it is something quite valuable.

This programme fulfills my needs.

I think you all do a good job. I can't think of any way you can improve this Programme.

I think this Programme, the way you are dong it, is absolutely fine. There is really nothing more that you can do. You are covering all that is needed.

Increased access to services was suggested by a number:

A way for the Programme to be improved in my opinion and experience is for the services to be more broadly available, as in consultation times longer, rather than just an afternoon or evening. Why not a full day and evening to coincide [with the] opening hours of this Clinic.

I have a fear that with current participants at around 500, that your ability or capacity to provide the present level of services may be in jeopardy. If funding permitted would it be possible to increase the staffing as the present I fear are over worked or difficult to get in to see unless you plan a very long way ahead.

It would be wonderful if more masseurs were available.

One participant mused about the educational impact of the Primary Health Care approach and ended up endorsing it:

I don't know how it can be improved. I casually wonder if there are some educational models that could come out of the program, e.g. a Web page that shows some of the clear outcomes - has stories of people coming to terms with knowledge of sexual health practices - provides links to selected health care sites. Certainly those involved in the program are subtly being educated and perhaps that is the most effective method. However, to develop such educational models could interfere with the quality of the program as it now 'happens'. Perhaps it is better to recognise the success of this model is in its coherency.

The majority of participants took this opportunity to provide further positive feedback however, and a number of themes emerged.

Many emphasised the gay-sensitivity of the Programme as essential but felt that this was handled with appropriate subtlety:

There is a comfort about this locale (O'Brien St). One is comfortable that being a gay male is the norm here and for all of us this is not an unusual thing. Being gay is not the thing that makes us unique. Being a brilliant Accountant, or Tennis Player, or Judge is the quality that makes us unique not our sexuality. At O'Brien St, we can comfortably put our sexuality in the background and get on with our health care matters.

I feel the aims of the program are being achieved in so far that all the services for gay people are available under the one roof without the hassle of going to a hospital and the problems involved with confidentiality and waiting to be seen, etc.

It is so comfortable and comforting to know this service is here. It is presented without fuss - a natural and caring part of life in Adelaide. Just fantastic!

This Programme and clinic is non-threatening. There is never ever any worry about the fact of my sexuality. I feel comfortable coming here. I feel a great sense of privacy when I am here.

Program has been very helpful to me in accessing coordinated holistic care from people sensitive to the specific needs of gay men. I now feel more confident in accessing any medical care and being more open with medical and allied health practitioners about my health. I hope the program continues.

I am pleased to know that there is a holistic gay service here in Adelaide. Run by gay men and women or those who are absolutely relaxed about it all. This is an important element - knowing that one can feel absolutely comfortable coming here.

HIV expertise and the use of a team approach to maximise this were also seen as important features:

This programme is essential for HIV+ people so that it gives a comprehensive management. I have been HIV+ for 12 years and have had to develop my own programme similar to [this one] to continually maintain my health. This was a difficult process and one which now has been addressed by this project by having this variety of services in the one building. This type of approach stimulates the individual's awareness, like a help-line, that there is a health service out there devoted to help and encourage them. It opens avenues, ie different professionals view-point, for oneself, especially with regard to side effects. This means that I don't feel that I am fighting this disease on my own.

I think this Programme is great. [In another capital city where I lived] there is nothing like it. From the moment I walk in here there is a positive feeling. I can't put a finger on it, but the overall feeling of the Practice whether it was the Reception, the Nurse, or the doctor or just simply waiting in the waiting room there was always a friendly feeling. What I also liked about my care here is that if my own doctor was unsure about issues relating to my care [the doctor] would discuss this with [a more experienced Programme GP]. This was comforting to know.

The program has been a great facilitator in health care for positive people, a quick, easy access, multi disciplinary team, even though I have no need to use most members, is a reassurance in itself. The only way it can be improved is for it to be duplicated in other access sites across the city and rural areas.

Coordination of service and holism were also seen to be key features of the Programme:

Have found the program to be very worthwhile. Providing a number of services under one roof make health management manageable. The staff involved provide an excellent service in dealing with the health and welfare of their clients.

*The programme has been very beneficial and knowing that* [the Nurse Coordinator] *is there to answer any questions/queries is comforting and reassuring.* 

The program is all encompassing. Many aspects of the program are unique in that it is easier to access all the services under one roof so to speak. The service providers are all respectful, easy to talk to and make me feel like I'm not losing it. This program should be available nationally.

I believe the programme is helpful to people to know where their health is at, to know if they are staying healthy and what and where to get any help necessary.

I believe that this Program fills a very big need in the community. From the time that I walked through the main entrance, from [the reception team] onwards, everything works towards the benefit of the patient.

This Program has taken away the isolation of coping by yourself. [A particular public hospital] provided some services, but I did not feel comfortable in that environment. Coming here makes me feel secure. I feel that my care by whoever I see at this Practice is holistic. They are informed about me, my notes are contained and available to all concerned in my care. I feel comfortable with this.

The program is beneficial for providing for those who are under resourced, lacking in confidence, or on their own. It provides a basis for development physically and emotionally, and gives those who need it a feeling that somebody is interested in, and cares about, their state of well being.

I believe this programme had been a very worthwhile thing to set up. It has been good for the community because there was nothing like this before. It is good also because I feel a support network is in place. I just have to make one phone call and I feel that this would set wheels in motion.

It needs to continue. I think the usefulness of the coordination of services and support for practitioners and thus better services for patients is paramount.

I like a medical [service] like this because I feel free to liaise with whoever I see about any issues that I wish to speak about regarding my overall health. This includes my physical, emotional and sexual health. It is nice to know psychologically that I have a stand-by such as this service.

I think this Programme is excellent. It treats the general health of the overall person, the physical, biological, mental, etc. It far outweighs any other practices I've used for total health care. It has also heightened my awareness to take some responsibility to take care of my own general health.

A number of participants also commented about the impact of the Programme on their lives:

I am very glad that you are here. It has made a remarkable difference to my life.

*I found the programme to* [be] *of great benefit to myself, and as such am greatly appreciative of its existence.* 

I am glad that I have had someone to talk to, knowing that there is help available.

This programme has been good for me. As I am a low income earner being able to come here and use these services has been an enormous benefit to me.

I feel that I have reached a better state of mind and health.

As soon as I walk through the door and into the reception area I am made to feel as though I am the most important person who comes here. But this, I have noticed, they do to everyone who walks in. This is tremendous. I think this Programme is great. It has been very good for me. I think that this Programme has allowed me to identify my problems more successfully and start to do something about them. Without this Programme my health would be considerably worse.

I believe that this Programme has been very beneficial to its target group. I have lots of reason[s] to think this, including friends who I know are participants who also feel the same. Only one of my acquaintances has spoken negatively about the Programme, but then he speaks negatively about everything.

I think this Programme has helped me enormously during a critical time of my life.

# Reflexive practice and organisational learning

As Legge has pointed out (see page 98), the 'discourse of outcomes', is in some senses antithetical to the Primary Health Care approach since it 'tends to discount the existential dimensions of health care and the quality of personal relationships because these are not measurable and cannot be reduced to a single objective indicator'.(Legge *et al.*, 1996a, p 21) It has also been argued that a focus on 'outcomes' implies reference to external standards rather than definitions of success that are derived from the affected community. The subjective assessments and qualitative analysis already discussed provide methods to address quality and accountability while avoiding this philosophical conflict, but so do the processes of critical reflection and organisational learning that Legge's group recommends (see page 98).

These practices have been central to the Care and Prevention Programme's approach since it began in 1998. The C&PP team has met almost every week (under the author's leadership), across the life of the Programme, to reflect critically on the processes used and the results observed, as well as to identify and consider methodological refinements. In addition, it has consulted frequently with the community it serves through informal discussion with participants, representation on the Management Committee and larger scale feedback and planning events.

As such, it has had the characteristics of a 'learning organisation' and it is the belief of the members of the Programme team, garnered through this process, that the resultant endeavour has been effective in improving the health status of its participants.

# Discussion

Overall, participants in the C&PP appear to have been very satisfied with the Programme. Their comments provide subjective confirmation of the health improvements documented in the previous chapter. Moreover, many participants expressed their belief that the health and wellbeing improvement they had experienced had *resulted* from their participation in the Programme.

They described factors like acceptance, comfort and the ability 'to be oneself' among the characteristics of the Programme that have facilitated their health improvement.

This subjective attribution of effect is particularly important because the C&PP's history of being developed as a service delivery endeavour, rather than expressly as a research project, means that no randomisation or control group were employed. Thus, though it has been possible for the Programme team to measure and document health improvement among participants in association with participation, it has not been possible to confirm a 'cause and effect' relationship between the Programme and the health benefits seen, by quantitative methods.

The subjective ratings and qualitative data presented in this chapter make it clear that participants in general believe that the Programme has met their needs and brought about health improvement.

Further, the beliefs of the members of the C&PP team, developed and identified through the processes of critical reflection and organisational learning are congruent with those of the participants in this regard.

These two results can be seen as forms of data triangulation for the quantitative outcomes data, which support the hypothesis that the Programme has been significantly responsible for the health improvement observed.

The three evaluation techniques taken together provide convincing support for the assertion that this application of the Primary Health Approach has indeed mitigated some of the health inequity experienced by the men who enrolled.

# PART FIVE <u>Conclusions</u>: What were the findings, what are their limitations and what are their implications?

# Chapter 12: Summary of Findings

This thesis set out to consider the health of homosexually active South Australian men in the context of two interrelated theoretical ideas: the health inequity framework with associated ideas concerning the social production of health, and the Primary Health Care approach to interventions for the improvement of the health of humans.

# The health inequity framework

This is a concept that flows from Universal Declaration of Human Rights, (United Nations, 1948) but was anticipated by earlier work in public health such as the al., 2000) contributions of John Gaunt, (Berkman et and Edwin Chadwick. (Chadwick, 1842/1965) The idea was further developed in the 'Black Report', released in 1980, which found that there was a distinct gradient in mortality across the 'social classes' in Britain such that the least privileged had more than double the chance of dying prematurely compared with the most advantaged group.

The notion of health inequity was crystallised by Margaret Whitehead, who was at the time working in the European Office of the World Health Organisation, in 1992. She pointed out that not all inequality in health between groups is inequity, noting that:

the term "inequity" has a moral and ethical dimension. It refers to differences [in health that] are *unnecessary* and *avoidable* but, in addition, are also considered *unfair* and *unjust*. (Whitehead, 1992, p 431, original emphasis)

Beginning with the work of John Cassel in the 1940s, the science of social epidemiology has attempted to delineate the mechanisms by which social conditions bring about health outcomes in human populations.(Krieger, 2001a) In this field of endeavour there has been a tension between what has been called a 'downstream' orientation, which focuses on mechanistic explanations based on the pathological processes and supposed free 'lifestyle choices' of individuals, and an 'upstream' perspective based on collectivist and holistic foundations that seeks structural and systemic explanations for ill health in populations.

Krieger, among others, has proposed that 'multi-level frameworks' for understanding health production have the potential to shift this debate from an ""either/or" to a "both/and" logic' by incorporating both orientations into an appreciation for the complexity of the production of health outcomes.(Krieger, 2001a, p 671)

# Primary Health Care

This approach to improving human health evolved during the early development of the World Health Organisation and came to maturity in the 1970s in the context of increasing dissatisfaction with the failure of the expensive technological and individually-oriented nature of Western medicine to impact on the health of populations. Examples of alternative approaches were also becoming apparent at this time, such as the community health movement in Australia (perhaps best exemplified by the Redfern Aboriginal Medical Service), the Indian rural medicine system and the Chinese 'barefoot doctor' scheme.

The Primary Health Care approach was formalised in the Declaration of Alma Ata in 1978, as:

essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in a spirit of self-reliance and self-determination.(Declaration of Alma Ata, 1978, Article VI)

It is a methodology that (in common with the health inequity framework) emphasises the economic, sociocultural and political determinants of the health of populations and calls for coordinated action in other sectors such as 'agriculture, animal husbandry, food, industry, education, housing, public works [and] communications' to improve human health.(Declaration of Alma Ata, 1978, Article VII) It emphasises multidisciplinarity in health care and community participation in the development and direction of health programmes.

The Primary Health Care approach was further developed with the expansion of notions of health promotion through the Ottawa Charter (1986) and the Jakarta Declaration (1997). It steered Australian health policy through much of the 1980s and early 1990s with notable results including the remarkable containment of HIV infection in this country.

PHC has had its critics, however, since very soon after the Declaration of Alma Ata and since the middle 1990s they have been gaining in influence. This has seen a shift back toward individually-oriented, 'vertical' programmes (that is programmes focused on particular diseases rather than health more generally) that are imposed by 'experts' rather than being developed in partnership with the affected community.

There has also been confusion (and, some have argued, deliberate obfuscation)(Keleher, 2001) about the term 'Primary Health Care' and its relationship with 'primary care' and 'general practice'.

Notwithstanding the policy trajectory in many jurisdictions, the Government of South Australia has recently moved against the trend by signing the Adelaide Affirmation for Primary Health Care in 2003.

# Homosexually active men

The history of the construct of homosexuality was considered and concepts of sexual attraction, 'orientation', identity and behaviour differentiated. What is known about the health characteristics of homosexually active men in the First World was then surveyed. It was concluded that there is evidence that they are affected by substantial health inequality in a range of areas including mortality, suicidality, depressive disorders, anxiety disorders, report of childhood sexual abuse and problematic substance use. Few of these inequalities had been confirmed in the Australian context, however, and almost none had been confirmed specifically in South Australia.

# The Care and Prevention Programme

The background to the development of this South Australian Primary Health Care programme, focused on homosexually active men, was described. The health characteristics of the cohort of 542 men who had enrolled in the Programme to June 30<sup>th</sup>, 2003 were explored and compared with those of other populations of men.

It was concluded that these men were subject to health inequality in a wide range of health parameters including mortality, suicidality, sexually transmitted infections, depressive and anxiety disorders, levels of substance use and self-rated health on the short-form 36 instrument.

The social and historical correlates of these health characteristics were then explored. It was concluded that many of the health inequalities identified were related to sociohistorical factors such as emotional withdrawal by one's father, low income, unemployment, reduced educational attainment, and recent experience of violence and abuse from strangers. It is argued that these factors can be considered to be examples of unfairness and injustice and that, as a consequence, at least some of the health inequality experienced by this population is also health inequity as defined by Whitehead.(Whitehead, 1992)

It was argued that the production of adverse health outcomes among homosexually active men is complex and that sociohistorical factors are woven into their health profiles together with a range of other parameters in the intricate fractal figure of health determination predicted by multi-level models such as Krieger's eco-social theory.(Krieger, 2001a)

The health-related characteristic of 'sexual behaviour that might provide a context for further HIV transmission' was also considered. It too was found to have complex determinants but social factors such as unemployment, as well as states of mind that were themselves related to social context, were found to be involved.

# 'Outcomes'

The elements of the Primary Health Care programme provided to C&PP participants were then described and the trajectory of the health characteristics of participants while they were participating was charted.

It was seen that among the 210 homosexually active men who had reached Second Review, an average of thirty six months after enrolment, by the time of analysis, significant improvement had been seen in a range of health parameters.

Participant's subjective satisfaction with the Programme was then described and their beliefs about the causes of their improved health explored using a qualitative methodology. It was concluded that the Programme had largely met the needs of participants and they believed that it had been responsible for their improved health.

The final evaluative approach described was the process of critical reflection and organisational learning undertaken by the Programme team in consultation with the community the Programme serves. The beliefs of the members of the team about the positive impact of the (continuously refined) Programme activities on the health of participants, developed through and identified from this method, accords with the belief of participants themselves discussed above.

Thus, it is argued in summary, homosexually active men *are* subject to health inequity and that inequity *can* be mitigated to some extent by the application of a programme based on the Primary Health Care approach.

# Chapter 13: Limitations of the Study

As was discussed in Chapter 4, the Care and Prevention Programme arose, as Primary Health Care programmes should, from a partnership response between a community and health professionals to an identified health need. It was developed to meet that need and while it was always intended that it be appropriately evaluated, the Programme was not originally set up as a research project.

Consequently, it was not constructed as either a population health study with a deliberate comparison group (for its investigations of health inequality) or as a randomised controlled trial with a control group (for its assessment of the impact of a Primary Health Care programme).

As the Programme unfolded, in the process of critical reflection by the team and community representatives, it became clear that the C&PP data could contribute significantly to knowledge about the health of homosexually active South Australian men, its determinants and the impact of a Primary Health Care programme upon it. In the light of this, it was decided that it would be in the best interests of the community it served for the research aspects of the Programme to be formalised (see also Chapter 4 on page 225). The outcomes of this decision form the basis for this thesis.

Some of the potential limitations of the study arise from this history.

A description of the limitations is also influenced by the mixture of methods this analysis has employed.

The investigation and comparison of prevalence of health conditions undertaken to identify health inequality was essentially an observational quantitative epidemiological study, as was the search for social correlates that sought evidence of health inequity.

The assessment of the impact and outcomes of the Primary Health Care programme was, on the other hand a quasi-experimental design with assessment at enrolment and at two timepoints during the 'intervention'.

It used mixed methods including quantitative, (relatively) objective measures but also quantitative subjective measures of satisfaction, qualitative assessment of beliefs about services and outcomes as well as a critical reflection evaluative methodology within the Programme team.

Each of these elements and methods raise different questions about validity and thus the potential limitations of the claims that may be made.

For the inquiries concerning the presence of health inequality and health inequity, the most important methodological concerns are issues of 'conclusion validity' (the degree to which conclusions reached about relationships in the data are reasonable) and 'external validity' (the degree to which the conclusions from the study would hold for other persons in other places and at other times).(Trochim, 2005) External validity is almost equivalent to the concept of 'generalisability'.

For the impacts and outcomes assessment, there is additional concern about 'internal validity', that is whether a causal relationship between the intervention and the result can be established.

# 'Validity'

Before discussing the validity of the elements of the Programme, it is worth making mention of the contested nature of the very concept of 'validity'. The Oxford English Dictionary's relevant definition of the word is:

The quality of being well-founded on fact, or established on sound principles, and thoroughly applicable to the case or circumstances; soundness and strength (of argument, proof, authority, etc.).[Simpson, 2005  $\#61\@$ , NPN]

A good translation into the research context comes from Trochim, who defines it as 'the best available approximation to the truth of a given proposition, inference, or conclusion'.[Trochim, 2005 #377\@, NPN]

'Validity' is thus a construct of the modern project, closely related to ideas like 'fact' or 'truth'. It posits the existence of an objective reality independent of human observation of it, thoughts about it and descriptions of it.

This position has been challenged by a procession of thinkers in the last century or so, that began with Nietzsche but has mostly been populated by French philosophers of the Twentieth Century such as Foucault<sup>\*</sup>, Derrida, Baudrillard and Lyotard. These strands in recent thought, most often described as 'postmodern', emphasise contingency and relativity as well as the effective equivalence of power and knowledge (or 'truth').

These ideas unsettle the whole belief system on which notions like validity, reliability and objectivity stand. Having regard for this view of the world, some qualitative researchers, such as Guba and Lincoln, have proposed alternative ways of assessing the 'soundness' or 'quality' of research results, that rely less on assumptions about objective and absolute truth.(Guba *et al.*, 1989) Some of these ideas will be incorporated into this discussion, alongside the more traditional concepts of internal and external validity.

# Measuring health inequality

One of the most important determinants of a study's external validity is its sampling method.

Most of the research that has informed the development of the health inequity framework and the science of social epidemiology, from the Black Report onwards, has looked at whole populations or probability samples of populations. Both health outcomes (such as mortality) and candidate health determinants (like 'social class' or income) have been identified from either censuses and registers for complete ascertainment of a population (as in the Black Report, 1988), or from sampling methodologies formulated in advance to be representative of a population in particular ways (as in the National Drug Strategy Household Survey, Fitzsimmons *et al.*, 2000).

<sup>&</sup>lt;sup>\*</sup> Whose work has also been considered in regard to the nature of sexuality and sexual identity – see page 124.

Sexual 'orientation', sexual attraction and sexual behaviour are not collected in the Australian census currently<sup>\*</sup> and so whole population ascertainment with regard to these attributes is unlikely to feasible in the immediate future. Consequently, studies such as the Australian Study of Health and Relationships, that have sought to compare health characteristics across sexual categories, have relied on methods such as quasi-random telephone number dialling to achieve samples including a representative proportion of homosexually active or gay-identified people. It is generally believed that such 'probability' methods are likely to produce samples that are most representative of a whole population and thus provide the greatest external validity. They may not, however, be the most appropriate way to sample a relatively small subgroup (like homosexually active men) within a population, particularly if the group is stigmatised. Probability methods are generally large scale, expensive and, for the reasons discussed on page 182, may, for all this, tend not to find a proportion of the people of sexual diversity present in the sample. They may even have a systematic bias toward missing those with greatest health impairment.

Consequently, most of the research on the health of people of sexual diversity (see Chapter 3) has used convenience samples of one kind or another. Such sampling is traditionally considered to be more liable to various kinds of bias such as recruiting only a subset of the 'true' population of homosexually active men that is different in important ways from people not recruited (though as has just been discussed the use of 'probability' samples to identify stigmatised people may also introduce systematic bias). These issues must be borne in mind when the meaning of the findings of such research is considered.

The Care and Prevention Programme sample is a convenience sample, in the sense that it comprises a group of homosexually active men identified for another purpose (the provision of health care). In addition, it is to some extent also a 'clinical' sample, since people may have been recruited when they presented to their general practitioner for management of a particular health problem and thus might have been 'selected' to some extent for ill health.

 $<sup>^{</sup>st}$  Though same sex couples can be identified and the Australian Bureau of Statistics has recently, for the first time, published some of the characteristics of the 37,774 such couples identified in the 2001 census. (Australian Bureau of Statistics, 2005 142)

This issue is discussed in detail on page 232 where it is argued that, since the majority of Australians attend a general practitioner during any year, and the C&PP recruited over a five year period, its sample is probably more 'population-like' than, say a hospital emergency room sample would be.

Nonetheless, the C&PP enrolment data are probably at their most meaningful, in terms of external validity, where they have been compared with other samples of men recruited in general practice settings.

Another issue that needs to be borne in mind in this analysis relates to a kind of 'construct validity' (the degree to which inferences can legitimately be made from the operationalisations in the study to the theoretical constructs on which those operationalisations were based).(Trochim, 2005) It was seen in the discussion that starts on page 132 that there are several classifications of sexual diversity that might be invoked when one talks about 'gay men' or 'homosexuals'. The group might be delineated in terms of its members' subjective sexual attractions, their objective sexual behaviour, their self-professed sexual identity or their attachment to a particular community. This thesis has tried to be very clear about which of these constructs is invoked and when, but these differences are important when the external validity of the study is considered. The study could definitely be expected to predict what would be found if the health of homosexually active men engaged with a gay-focused general practice centre in the city of Adelaide were examined. The extent to which it would predict the findings of a study with an identical sampling methodology undertaken in Perth, Western Australia, or a study of gay-identified men recruited through a social group in Mount Gambier in the South East of South Australia is less certain. This requires delineation of exactly what is meant when 'the health of gay men' or even 'the health of homosexually active South Australian men' is discussed.

For many of the health characteristics considered in Chapter 5, significant health inequity was demonstrated when the cohort was compared with a range of comparison groups including samples from Australian general practice and other First World primary care samples.

For others, health inequity affecting 'homosexually active South Australian men' can only be inferred from the degree of difference between rates in the cohort and those among population samples of Australian men generally. This must be borne in mind when the validity of the health inequality findings is considered.

Another way to look at these issues is through the lens of Guba and Lincoln's This is roughly analogous to external validity or concept of transferability. generalisability but it does not require reference to notions of an objective and discoverable truth 'out there' about the population from which the sample was drawn.(Guba et al., 1989) In this framework the issue of the applicability of the findings to settings other than that from which they were drawn is essentially an issue for the would-be interpreter. The researcher's task is to describe the sampled setting in sufficient detail to allow the reader to make a reasoned judgement about whether the findings would be meaningful in the other setting that they have in mind (as was done in Chapter 5 on page 231). The fact that this approach is usually applied to qualitative methodologies does not mean that it would be inappropriate to use with the C&PP data for an interpreter of postmodern bent. When considered in the context of quantitative data it can be seen that the ideas that inhere in transferability cross over with the kinds of (non-statistical) judgements that readers make about issues such as the likely impact of a convenience sampling methodology on the (traditional) external validity of a study.

# Identifying health inequity

The methodology for the identification of health *inequity* (as defined by Whitehead, quoted on page 39) involved comparing the presence or severity of health characteristics that had been proposed as examples of health inequality, with social and historical factors that might be indicative of unfairness in their causation. This involved analysis of a wide variety of health characteristics and sociohistorical variables. Much of this was done retrospectively<sup>\*</sup> and so might draw an accusation of 'data-trawling' or 'data-dredging' in pursuit of significant associations.(Davey Smith *et al.*, 2005) This raises a concern about 'conclusion validity' as discussed above.(Trochim, 2005)

<sup>\*</sup> Though the extended sociohistorical variables (see page 347) were added at Second Review in order to investigate postulated associations prospectively.

Some would seek to apply more stringent measures of significance in such circumstances such as the Bonferroni adjustments discussed on page 328. As Rothman,(Rothman, 1990) and Perneger (see page 353) (Perneger, 1998) have pointed out however, in epidemiological studies, type II errors (failing to find true associations to be significant) and what Michels and Rosner have called 'type zero errors' (failing even to look for important associations that actually exist), (Michels *et al.*, 1996 1152) are more serious problems than type I errors (falsely finding chance associations to be meaningful). As Michels and Rosner put it:

False positives – especially if described for the first time – ... will stimulate further research and be disproven when more data are obtained. Any one study is not the beginning or the end of human knowledge and confirmation by other studies is generally sought for new discoveries made.(Michels *et al.*, 1996 1153)

Many of the associations reported in Chapter 5 appear to be robust and remain significant even when adjustment for multiple comparisons is made, but others are more subtle and may require confirmation in the future.

Since the construct of 'health inequity' has proven to be robust in recent discourse, however, (that is, one instance of 'health inequity' can be taken to mean similar sorts of things to another) it is legitimate to consider various examples demonstrated in the study as a coherent whole. Taken together, they provide definite support for the applicability of the health inequity framework to the health of homosexually active men.

# Measuring the impact of the PHC programme

As has been pointed out, the Care and Prevention Programme was not set up as a clinical trial. In keeping with the principles of the Primary Health Care approach, it arose from a community/health care worker partnership response to identified health needs. Neither the community that drove it, nor the government departments that funded it, would have accepted strategies like randomisation or the denial of what were seen as needed services to a 'control group'.

Thus, although its assiduous health assessment and record keeping have demonstrated clear improvement of the health of participants (on average) in association with participation in the Programme, no definite assertions can be made on this basis about the C&PP actually having brought about these improvements. In other words, its design has difficulty verifying internal validity.

There are six traditional concerns about internal validity in a 'pretest/intervene/post-test design, such as the 'objective' quantitative component of the Care and Prevention Programme evaluation.(Trochim, 2005) The first is the notion of 'history', that is, that some other influence other than the programme brought about the health change. As has been discussed, it is difficult to imagine any other factor that might have brought about such a coherent improvement, particularly since the policy environment in Australia during period concerned was, if anything, going in a direction that might have been expected to have a negative impact on the well being of people of sexual diversity. Nonetheless there may be a factor that has not occurred to the Programme team, and on the basis of the 'objective' data only, this possibility cannot be discounted with this quasiexperimental design.

The second traditional 'threat' to internal validity is the notion of 'maturation', that the sampled group improved simply because they had become older in the interval between two measures. The short period between enrolment and first review (a mean of about eighteen months) is thought to be too short for sufficient normative development to have occurred in men whose average age was around 40 to bring about the health differences that were observed. Thus the 'maturation' effect is thought unlikely to be important. Had the sample been aged around 16 at enrolment, the issues might have been quite different.

The third internal validity concern is the 'testing' issue – that undertaking the first assessment influences performance in the second. The eighteen month period between the first two assessment seems intuitively to be too long for a 'practice' effect to have occurred.

If on the other hand the performance of the first assessment actually had a *therapeutic* effect (through mechanisms like the participant feeling that the Programme team were interested in him and cared about him) that effect may properly be considered to have been an intended benefit of the Programme (what the evaluation is trying to demonstrate) rather than an artefact.

The fourth traditional 'threat' to internal validity in this design is the 'instrumentation' issue. That is, that the testing method was some how different and this brought about the apparent change. This is not thought to have been a significant problem in the C&PP because the same questions and questioning technique (on screen completion) were used at all assessments.

The fifth traditional 'threat' is the so-called 'mortality effect'. This refers not to death of participants but biasing due to loss of some participants from the study between assessments and those who were lost differing in a systematic way with regard to outcome. The repeated measures analysis used in the study would be expected to eliminate this effect as a concern.

The final issue is 'regression to the mean', whereby individuals who have a lower level of health than is average in a population at one time point will by chance alone be more likely to be closer to the average level on a subsequent assessment and thus will appear to have 'improved'. This certainly is an important concern in the present study. It might also have been exaggerated by the somewhat greater likelihood of participants being (temporarily) unwell at the time they were recruited because of the recruitment methodology through general practice. Because the 'mean' levels of health for the population from which the sample was drawn (whatever that actually means in this setting) are unknown, formal statistical calculations of the predicted degree of regression to the mean cannot be undertaken. What can be said is that while the apparent improvement in the physical measures of health between enrolment and First Review seems likely to have resulted from this phenomenon, the continuing improvement seen in many of the psychological measures across three timepoints is thought unlikely to have arisen in this way.

It can also be seen that, on the basis of qualitative analysis of their comments, many of the participants in the Programme *believe* that participation in the Programme brought about their health improvement (see page 442).

Further, as Legge has argued (see page 98) rigid methods like the randomised clinical trial are potentially problematic in the context of Primary Health Care, which defines success in terms specific to the community from which it springs and resists the imposition of externalised standards of quality or ideas of what a successful outcome looks like.(Legge *et al.*, 1996b) Processes like critical reflection and organisational learning in the pursuit of 'best practice' advocated by Legge for the assurance of quality in PHC programmes (see page 98) may be more appropriate measures of impact. In these terms, the C&PP Programme team (under the author's leadership) has met almost every week since 1998 to discuss its observed effectiveness and has consulted its community both formally and informally on numerous occasions. Through this process, its workers (in accord, it would seem from the qualitative data, with its participants) believe that they have observed a continuing and continuously improving positive impact on the health of participants.

These two methodologies serve as 'triangulation' methods that support claims of internal validity for the quantitative analysis (that is, that the Programme brought about the observed health improvement). Triangulation with the results of the qualitative analysis also introduces the notion of 'credibility' as proposed by Guba and Lincoln.(Guba *et al.*, 1989) In this construct what is required is to establish that the results of a (usually qualitative) study are 'credible or believable from the perspective of the participant in the research'.(Trochim, 2005) The qualitative results presented include the clear theme of health improvement having been brought about by participation and so claims of such 'success' appear to be credible.

# Summary

It can be seen that there are some potential limitations to the findings presented that result from the Programme's history, the clinical convenience sampling method and the 'quasi-experimental' design of the evaluation component. It has been argued, however, that the effect of these limitations can be reasonably anticipated and on this basis does not appear to impair the validity of the component parts of the study to an important extent. Further, continuous dialogue between participants and the members of the team, as well as the multiple methods used in the evaluation component, have provided the opportunity for data triangulation that supports the conclusions made.

Thus, despite the limitations, it can be reasonably concluded that homosexually active South Australian men experience significant health inequity and a clinically relevant therapeutic effect on this inequity resulted from the Primary Health Care programme provided.

# Chapter 14: Implications of the Study for Future Policy, Practice and Research

# **Policy & Practice**

Although it is often couched in terms of 'health inequalities' rather than inequity *per se*, the discourse of a health inequity framework, which followed from the Black Report and was fully developed by Whitehead (see page 39), continues to resonate in many corners of the world at the midpoint of the first decade of the Third Millennium.

It has been argued in this thesis that (with a very few exceptions such as the efforts of Ruth McNair in Australia, (McNair, 2003) and recognition by Krieger in some of her writing (Krieger, 2000 41)) health inequity experienced on the basis of sexual diversity has been missing from that discourse.

Thus people whose sexual attractions, behaviour or identity are bases for discrimination and disadvantage in the societies in which they live are doubly disenfranchised. They experience the health consequences of bigotry and hatred to which they are subjected by those who would condemn them for feelings and actions that, as has been argued, harm no one and are nothing more than their right as humans. Then, they are further marginalised, though often unintentionally, by people of goodwill working in health policy and practice who fail to see and validate their experience of oppression.

The origins of this 'blindness' are complex and beyond the scope of this discussion. There is no doubt, however, that its genealogy includes the proclamations of organised religion and the policing of gender roles that underpins patriarchy in many parts of the world. In the West it is also supported by myths of the 'advantaged Other' that can be seen in the discourse of the Pink Dollar (that gay men, in particular, are all financially well off), as well as in the rantings of former federal politician Pauline Hanson about the supposedly unfair government assistance available to Indigenous Australians.(Hanson, 1996 3860)

This study has investigated and confirmed the presence of health inequity affecting South Australian homosexually active men and pointed to its likely presence among many communities of sexual diversity.

The complete resolution of this inequity will require profound social change. It would involve a fundamental re-examination of the conventions of sexual and gender expression and the ways that they are 'policed' in human societies. Such social change would allow 'gender atypical' children to be able to rely on their parents for support and affirmation, enable people of difference to obtain an education on an equal footing with the majority, afford them equality of opportunity in employment and housing, and allow them to hold the hands of their life partners in the streets of our cities without fear of abuse or violence. In other words, it would impact on the social determinants of their health, most of which are not in the sphere of health care.

As this chapter is being written, the Parliament of South Australia continues to delay the passage of legislation that would make long-term loving relationships between people of 'the same gender' equal under the law with similar relationships between people of 'different genders'. Since South Australia is the last jurisdiction in the country without such legislative equity, the importance of structural societal change to improving the health and wellbeing of people of sexual diversity is thrown into particular relief in this place at this time. Further, there are very many small but important steps that will need to be taken after this one in the journey to a just society.

What this study has also demonstrated, however, is that a Primary Health Care programme that is specifically focused on providing culturally safe and appropriate whole person care to people of sexual diversity can mitigate some of the health consequences of an unjust society.

In the light of the identification of the health inequity facing homosexually active men, there is a clear responsibility for policy makers to act to change the unjust conditions that create that health inequity. Further, it is argued, since the elimination of the social determinants of the health inequity will be a long and difficult process, there is a responsibility in the meantime to act to mitigate their effects by any reasonable and effective methods that are available.

People of sexual diversity have a right to expect culturally safe and knowledgeable help from 'mainstream' health care services. In reality, however, organisations without a particular focus on them will probably reflect the prevailing climate of the society of which they are part. Thus, they are unlikely, in the short to medium term, to be able to provide care without a real risk of aggravating health disadvantage by reinforcing societal oppression. Problems that may seem small can have significant health effects on people who are already vulnerable. When a young, same sex attracted male is asked 'do you have a girlfriend?' by a well-meaning GP, the unintended, implied invalidation of his relationship with his *boyfriend* amplifies the oppression he is already experiencing from his parents and peers and prevents the health care provider from helping effectively.

It is vital and urgent that efforts be made to improve cultural sensitivity to, and knowledge of, issues of sexual diversity on the part of health care systems and health care professionals generally. Such an approach will bear fruit slowly, however, and in the meantime gays and lesbians are literally dying from the effects of homophobia.

This study has shown that focused Primary Health Care with a community of sexual diversity works. It mitigates the health inequity its members experience and helps them to survive and function while they wait for a fairer and kinder society. This finding places a responsibility on health care policy makers to support such programmes, alongside improvements to mainstream services and attention to the broader social determinants of health inequity.

# Research

#### **Population health research**

The 'blindness' to health inequity on the basis of sexual diversity discussed in the previous section has been prevalent in health research as well as health policy. A lot of good work to investigate the health of people of sexual diversity has been undertaken but, as was seen in Chapter 3, much of this research has taken place within identified communities and relied on convenience samples.

Indicators for other bases for health inequity such as income, occupation, employment status, Aboriginality and geographical background are routinely sought in population and population health studies such as the Census, death and disease registers, and national health surveys. This allows the extent of health inequity on these bases to be studied for its effects at whole population levels. The absence of enquiry into sexual diversity characteristics in such large scale studies has hampered the acquisition of knowledge and has in turn contributed to the persistence of 'blindness' to the issue.

There are significant concerns about the collection of sexual diversity characteristics in large-scale studies, many of which have been discussed in the thesis. They include which characteristic(s) to collect, given the multiple ways (such as attraction, behaviour, identity) in which sexual diversity may be described, and issues around subjects feeling safe and comfortable to disclose in the face of continuing societal disadvantage<sup>\*</sup>.

None of these is insoluble, however. The C&PP data suggest that, at least for men older than about twenty, the various ways of measuring sexual diversity will identify roughly the same group of people and thus there is no need to hold up population research to identify the perfect measure. Similarly it is possible to include hypothetical questions about *whether* respondents would be prepared to disclose sexual diversity (should it be present) that would allow quantification of undercounting on the basis of non-disclosure.

Thus solutions can be found to the methodological problems of population research into the health of people of sexual diversity and it is urgent that they be implemented.

<sup>&</sup>lt;sup>\*</sup> This issue, of course, represents a vicious causation circle in that stigma causes nondisclosure which hampers research to overcome stigma, and so on.
#### Health service research

Just as effective population health research requires identification of people of sexual diversity so too does research into the effectiveness of health care interventions and health services. It would be unthinkable in a contemporary randomised controlled clinical trial to fail to account for the effects of variables such as gender or 'ethnicity' in drawing conclusions about the validity of a result. As we have seen, the health of people of sexual diversity is affected by the impact of societal oppression. Thus, it can be argued that sexual diversity characteristics should be reported on in health care trials in the same way as other demographic variables.

Allusion was made to some of the issues related to the evaluation of health care systems for specific communities in the last chapter. The 'gold standard' of the randomised controlled trial as an evaluation tool for an 'intervention' as complex and contingent as a Primary Health Care programme may not be very meaningful. Nonetheless, it is incumbent on providers of services, and the communities from which they arise, to assess them carefully for effectiveness and appropriateness using the many other tools that are available. Such evaluation plans need to be designed into programmes as they are developed in the future.

Some would argue that complex interventions *can* (and should) be evaluated meaningfully through randomised trials and the (UK) Medical Research Council has gone so far as to propose a 'Framework for development and evaluation of RCTs for complex interventions to improve health'.(Medical Research Council, 2000) This framework would regard the present study as a 'phase II trial' and would argue for the conduct of a 'definitive randomised controlled trial' (a 'phase III trial') designed through consideration of its findings. Whether such a large, expensive and necessarily reductionist and artificial undertaking would materially change the veracity of the conclusion that 'the application of the Primary Health Care approach can mitigate the health inequity experienced by homosexually active South Australian men' is open to debate. It could be argued that the funds and effort would be better directed to providing such a service or, better still, to changing the societal conditions that brought about the inequity in the first place.

# Appendices

# Appendix 1:

# Demographic questionnaire

The computerised on-screen demographic questionnaire was usually completed by the enrolling participant with assistance from the Registered Nurse only when the participant was technologically challenged.

The following data were collected:

Question	Question asked	Available responses	Data type collected
	Data of Accomment	Automatically recorded	Dete
2	UR Number	Sequential programme record	Alphanumeric
3	Please enter the first two letters of your surname	Free: 2 letters	Text (for name code)
4	Please enter the first two letters of your given name	Free: 2 letters	Text (for name code)
5	What is your date of birth?	Free: date	Date
6	What is your gender?	Male Female Transgender	Numeric code
7	In what country were you born?	Free	Text
8	In what country was your father born?	Free	Text
9	In what country was your mother born?	Free	Text
10	What language did your family speak at home when you were growing up?	Free	Text
11	Is there an ethnic group (other than Anglo- Australian) with which you strongly identify? (eg: Australian Aboriginal, Dutch, Greek, Vietnamese)	Free	Text
12	Which of these options best describes your accommodation situation?	Live alone Live with a female sexual partner (with or without children) Live with a male sexual partner (with or without children) Live with parents/relatives Live with gay friends (including one or more sexual partners) Live with gay friends (but no sexual partners) Live with straight friends (but no sexual partners) Other	Numeric code
13	We are interested in your work situation. Are you? (choose one)	Full-time employee Part-time employee Full-time self-employed Part-time self-employed Unemployed Student Pensioner or social security benefits Domestic duties Voluntary worker Not in the workforce	Numeric code

		Other	
14	How long have you been in this work situation?	0 - 5 months 6 - 11 months 1 - 2 years 3 - 5 years More than five years	Numeric code
15	IF less than 6 months, what was your previous work situation?	As for Q 13 above	Numeric code
16	What kind of work do you, or did you, do?	Managerial Professional Para-professional Trade Clerical Sales & Personal Service Plant & Machine Operation & Driving Labouring & Related Work	Numeric code
17	Has your workload increased significantly in the last six months?	Yes No	Yes/No
18	To which of these income groups do you belong?	\$0 - 4,000 \$4,001 - 9,000 \$9001 - 15,000 \$15,001 - 18,000 \$18,001 - 22,000 \$22,001 - 26,000 \$26,001 - 32,000 \$32,001 - 40,000 \$40,001 - 50,000 \$50,001 - 60,000 > \$60,000	Numeric code
19	What is the highest level of education you have had?	Primary School Only Up to 2 years high school Year 10 / 3rd Form / Intermediate Year 11 / 4th Form / Leaving Year 12/ 5th Form / Matriculation Tertiary Diploma or Trade Certificate Bachelor's Degree Second or Higher Degree	Numeric code
20	Do you have any religious belief?	None, atheist or agnostic Roman Catholic Anglican Other Protestant Other Christian Jewish Moslem Buddhist Other non-Christian	Numeric code
21	Are you, or have you ever been, married or in a defacto relationship with a woman? (DO NOT INCLUDE MARRIAGES OF CONVENIENCE)	Married De-facto Never	Numeric code
22	Do you have any children?	Yes No	Yes/No
23	Do any of your children live with you?	Yes No	Yes/No
24	In which town or suburb did you grow up? (If another city give city and suburb, if overseas give country only, if several places give place where spent most time in childhood)	Free	Text
25	What is the postcode of your current address?	Free: four digits	Number
26	How long have you lived there?	As for Q14 above	Numeric code
27	(If less than six months) In which town or suburb did you live previously? (If another city give city and suburb, if	Free	Text

	overseas give country only, if several places give place where spent most time in childbood		
28	Have you travelled overseas in the last five years?	Yes No	Yes/No
29	If so please indicate the countries you visited (or if >6 those in which you spent the most time). (If you went to Indonesia, please indicate whether you went to Bali or not)	Free: six fields	Text

# Appendix 2: Health baselines form

The computerised health baselines form was usually completed by the Registered Nurse in collaboration with the enrolee, and augmented with information from the medical record and the referring GP. The values for questions 14-19 and 58-64 were measured by the nurse during assessment.

The following data were collected:

Question	Field label	Available responses	Data type collected
number			
1	HIV Ab status:	Positive Negative Unknown Not Tested	Numeric code
2	Date of last HIVAb test:	Free	Date
3	HepA Total Ab status:	As for Q 1 above	Numeric code
4	Date of last HepA Total Ab test:	Free	Date
5	HepBsAg status:	As for Q 1 above	Numeric code
6	Date of last HepBsAg test:	Free	Date
7	HepBsAb status	As for Q 1 above	Numeric code
8	HepBsAbLevel:	Free: three digits	Number
9	Date of last HepBsAb test:	Free	Date
10	HepC Ab status:	As for Q 1 above	Numeric code
11	Date of last HepC Ab test:	Free	Date
12	Treponemal IgG status:	As for Q 1 above	Numeric code
13	Date of last Treponemal IgG test:	Free	Date
14	Blood Pressure:	Free: three digit integers x 2 fields	Numbers
15	Weight: [Kg]	Free: three digit integer	Number
16	Height: [Metres]	Free: three digit decimal (0.00)	Number
17	MidArmMuscleCircumference: [Millimetres]	Free: three digit integer	Number
18	TricepsSkinFold: [Millimetres]	Free: two digit integer	Number
19	Abdominal Girth: [Centimetres]	Free: three digit integer	Number
20	Smoking Status:	Never Smoked Quit >10 years ago Quit 1 - 10 years ago Quit in last year Smokes <5 per day Smokes 5 - 20 per day Smokes 21 - 50 per day Smokes >50 per day	Numeric code
21	Alcohol Use:	Never used (1) Previously heavy, now nil (1) Previously light, now nil (1) Occasional light drinker (2) Occasional binges (4) Regular 1 - 4 standard drinks most days (3) Regular 4 - 8 standard drinks most days (4) Regular >8 standard drinks most	Numeric code (recoded to nominal scale utilising numeric values in parentheses)

		days (5) Weekende 1 4 standard drinks 1	
		or 2 days per week (3)	
		Weekends, >4 standard drinks 1	
		or 2 days per week (4)	
22	Injecting Drug Use:	Never	Numeric code
		Last >10 years ago	
		Last 1 - 10 years ago	
		More than once a week	
		Nearly every day	
23	Sharing injecting equipment:	Never Shared	Numeric code
	0, 0, 1,	Shared only with sexual partner	
		Shared but ALWAYS cleaned with	
		bleach	
		Has ever shared without cleaning	
24	Cannabis Use:	Never Dravioualy, but not in last year	Numeric code
		At least once a month	
		Several times a month	
		Once a week	
		Several days each week	
		Every day	
05	NP4 ( 11	Several times every day	
25	Nitrate Use:	As for Q 24 above	Numeric code
20		As for Q 24 above	Numeric code
28	ESD USE.	As for Q 24 above	Numeric code
29	Heroin Use	As for Q 24 above	Numeric code
30	Has the person ever had a tattoo?	Yes	Yes/No
	····	No	
31	What year was the EARLIEST tattoo done?	Free	Date
32	Has the person ever had a piercing?	Yes No	Yes/No
33	What year was the EARLIEST piercing done?	Free	Date
34	Has the person ever had a blood transfusion?	Yes No	Yes/No
35	What year was the EARLIEST transfusion done?	Free	Date
36	Please list any prescribed drugs the person	Free: seven fields	Text
	takes, in this format: Drugname, tabletsize,		
	tabsperdose, frequency (eg: indinavir,		
	six drugs list the most important above and		
	others below.		
37	Please list any significant past medical history	Free: seven fields	Text
	listing the name of the disease, injury or		
	procedure followed by the year of onset: If		
	there are more than six entries, list the most		
20	Important above and the others below	No biotomy of LICV(	Numerie eede
30	some questions about Sexually-Transmitted	Facial/oral HSV only	
	Diseases and remind him that the information	Anal HSV only	
	stored in this database is coded and	Genital HSV only	
	completely confidential. Is there a past history	Anal/genital AND Facial/oral HSV	
	of HSV?		
39	Is there a past history of genital/anal warts?	No Hx of genital or anal warts	Numeric code
		Anal warts only	
		Both genital & Anal warts	
40	If yes, how were the warts treated?	None	Numeric code
		Podophyllin or podophyllotoxin	
		Other chemical treatment	
		Liquid nitrogen	

		Dry ice Diathermy Laser Surgery Systemic medication	
41	Is there a past history of syphilis?	Yes	Yes/No
42	If yes, how was it treated?	No Treatment Oral antibiotics Injected antibiotics as an outpatient Injected antibiotics as an inpatient	Numeric code
43	Is there a past history of Gonorrhoea?	Never had Urethral Rectal Pharyngeal Vaginal/cervical More than one site	Numeric code
44	Is there a past history of Chlamydia?	As for Q43 above	Numeric code
45	Is there a past history of NSU?	Yes No	Yes/No
46	Is there a past history of Clinical Hepatitis?	Yes No	Yes/No
47	What year?	Free	Year
	Has the person been Immunized for Hepatitis A?	Yes No	Yes/No
48	If so, what year?	Free	Year
49	Has the person been Immunized for Hepatitis B?	Yes No	Yes/No
50	If so, what year?	Free	Year
51	What is the state of the person's Father's Health:	Free	Text
52	What is the state of the person's Mother's Health:	Free	Text
53	Is there a Family History of Ischaemic Heart Disease?	No relatives with ischaemic heart disease 1x 2nd degree relative with IHD >60yrs 2x 2nd degree relatives with IHD >60yrs 2x 2nd degree relatives with IHD <60yrs 1x 1st degree relative with IHD >60yrs 1x 1st degree relative with IHD <60yrs 2 or more 1st degree relatives with IHD <60yrs	Numeric code
	polyps?	Polyps 1x 2nd degree relative with Ca Colon or Polyps 2x 2nd degree relatives with Ca Colon or Polyps 1x 1st degree relative with Ca Colon or Polyps 2 or more 1st degree relatives with Ca Colon or Polyps Diagnosed Familial Polyposis Coli	
55	Is there a Family History of Psychiatric Illness?	No family history of Psychiatric Problems 1 or more 2nd degree relatives with mood disorder or suicide 1 or more 2nd degree relatives with psychotic disorder	Numeric code

		1 or more 2nd degree relatives with substance disorder 1 or more 2nd degree relatives with OCD 1 or more 1st degree relatives with mood disorder or suicide 1 or more 1st degree relatives with psychotic disorder 1 or more 1st degree relatives with	
		substance disorder 1 or more 1st degree relatives with	
56	Is there a Family History of Diabetes?	OCD No FH of Diabetes	Numeric code
		One second degree relative	
		Two or more second degree	
		One first degree relative	
		Two or more first degree relatives	
57	Record any other significant Family History here:	Free	Text
58	Spirometry: FVC:	Free: Three digit decimal (0.00)	Number
59	FEV1:	Free: Three digit decimal (0.00)	Number
60	PEF:	Free: Four digit decimal (00.00)	Number
61	Urinalysis: Blood	Negative	Numeric code
		Trace	
		Small (+)	
		$\frac{1}{1} \frac{1}{1} \frac{1}$	
		(++++)	
62	Glucose	As for Q61 above	Numeric code
63	Protein	As for Q61 above	Numeric code
64	Leukocytes	As for Q61 above	Numeric code

# Appendix 3:

# Extended sociohistorical correlates questionnaire

These questions were administered in computerised form to participants attending for Second Review, an average of 36 months after enrolment in the C&PP

Question	Question	Available responses	Data type collected
number			
Preamble	In this Update we are asking some extra questions to enable us to better understand the sources of stress in participants' lives. Please remember that none of the questions is compulsory but your honest answers will help us to better understand the causes of distress in our community. Remember also that your name does not appear in this database and that there are strict privacy and confidentiality protections on the use of this information.	-	
-	Vinich of these phrases best describes your relationship with your biological FATHER during your EARLY CHILDHOOD?	He was not around during my early chilhood He was emotionally distant during my early childhood I remember an "average" relationship with him He was a strict disciplinarian We had a warm close relationship during my early childhood None of the above is appropriate	Numeric Code
2	Which of these phrases best describes your relationship with your biological MOTHER during your EARLY CHILDHOOD?	She was not around during my early chilhood She was emotionally distant during my early childhood I remember an "average" relationship with her She was a strict disciplinarian We had a warm close relationship during my early childhood None of the above is appropriate	Numeric Code
3	Were you sexually abused by a member of your immediate family before you turned 18?	Yes, I was sexually abused before the age of ten only Yes, I was sexually abused after the age of ten only Yes, I was sexually abused before AND after the age of ten No, I was NOT sexually abused before my eighteenth birthday	Numeric Code
4	Were you sexually abused by someone else before you turned 18?	Yes, I was sexually abused before the age of ten only Yes, I was sexually abused after the age of ten only Yes, I was sexually abused before	Numeric Code

		AND after the age of ten No. I was NOT sexually abused	
		before my eighteenth birthday	
5	Have you been forced to engage in sexual activity without your consent on	Yes No	Yes/No
	any occasion since your 18th birthday?		
6	Have you been verbally abused by a stranger in the last year?	Yes No	Yes/No
7	Have you been threatened with violence	Yes	Yes/No
0	by a stranger in the last year?	NO	N/ /N
8	Have you experienced physical violence by a stranger in the last year?	Yes No	Yes/No
9	Have you ever tried to take your own	Yes	Yes/No
10	lile?		Numerie Cada
10	If yes, now did you do it?	An overdose of tablets	Numeric Code
		An overdose of injected drugs	
		cliff	
		Other dangerous driving	
		Cutting wrists or elsewhere on	
		body	
		Hanging or strangling	
		Gunshot	
		Use or gas or car exhaust fumes Another method	

# Appendix 4:

# Abbreviations

All abbreviations are defined on first use in the text according to convention. In addition, they have been collected here to assist those who are reading only part of the thesis.

Abbreviation	Meaning
95%CI	Ninety-five percent confidence intervals
AIDS	Acquired Immune Deficiency Syndrome
ASHR	The 2001/2 Australian Study of Health and Relationships(Smith <i>et al.</i> , 2003)
BEACH	The Bettering the Evaluation and Care of Health study(Bayram <i>et al.</i> , 2003)
C&PP	The Care and Prevention Programme (including its developmental phase, known as The Care and Prevention <i>Project</i> )
C&PP cohort	The first 542 homosexually active men who enrolled in the Care and Prevention Programme
CIDI	Composite International Diagnostic Interview – a diagnostic protocol for 'mental disorders'
DD	Dysthymic Disorder as defined in the DSM-IV (see below)
DSM-IV	The Fourth Edition of the Diagnostic and Statistical Manual of the American Psychiatric Association – describes the criteria to be fulfilled before a particular disorder can be diagnosed(American Psychiatric Association. Task Force on DSM-IV, 1994)
FET	Fisher's Exact Test of significance
Futures II	HIV Futures II: The Health and Wellbeing if people with HIV/AIDS in Australia(Grierson <i>et al.</i> , 2000)
GAD	Generalised Anxiety Disorder as defined in the DSM-IV (see above)
HAM	Homosexually active men
HIV	Human immunodeficiency virus
HIV+	Known to be positive for antibodies to human immunodeficiency virus
HIV-	Found to have been negative for antibodies to human immunodeficiency virus on most recent test
HIV?	Has either not been tested for antibodies to human immunodeficiency virus or is not aware of the results of any test

	Includes men who either have been found to have been
	negative for antibodies to human immunodeficiency virus on
HIV-/?	their most recent test <i>or</i> have not been tested for antibodies to
	human immunodeficiency virus or are not aware of the results
	of any test
MDE	Major Depressive Episode as defined in the DSM-IV (see above)
MWT	Mann-Whitney Test
	Men who have sex with men. Includes all males who are
MSM	homosexually active regardless of whether they identify as gay,
	bisexual, heterosexual or something else.
	No date. Used for references from electronic and other sources
	where the date of writing or publication cannot be discerned.
	The 1998 National Drug Strategy Household Survey(Higgins et
1390	<i>al.</i> , 2000)
	The 2001 National Health Survey(Australian Bureau of
1011501	Statistics, 2002d)
NDN	No page number. Used for references from electronic sources
INFIN	with no discernable page numbers.
	The 1997 National Survey of Mental Health and
11311111197	Wellbeing(McLennan, 1999)
OR	Odds ratio
D	Probability that an apparently significant finding could have
F	occurred due to chance alone
PD	Panic Disorder as defined in the DSM-IV (see above)
Periodic (the)	The 1999 Adelaide Gay Community Periodic Survey(Van de Ven
Tenodic (the)	<i>et al.</i> , 2000)
	Primary Care Evaluation of Mental Disorders – a diagnostic
Prime-MD	instrument for depressive, anxiety, alcohol and eating disorders
	designed for use in 'primary care'(Spitzer <i>et al.</i> , 1994)
sf36	The Short Form 36 quality of life test(Ware, 1993)
ttWC	t-test with Welch's Correction
UAI-C	Unprotected anal intercourse with a casual partner
UAI-R	Unprotected anal intercourse with a regular partner
	Unprotected anal intercourse with a regular partner who was
UAI-KIIC	non-concordant for HIV status with the respondent
	The 2000 study of general practice attenders conducted in the
WHDS	Whitehorse Division of General Practice in the outer eastern
	suburbs of Melbourne(Griffith <i>et al.</i> , 2001)
WSRT	Willcoxon Signed Ranks Test

## **Appendix 5: Published paper**

Rogers, G., Curry, M., Oddy, J., Pratt, N., Beilby, J. & Wilkinson, D. (2003) Depressive disorders and unprotected casual anal sex among Australian homosexually active men in primary care. *HIV Medicine v.4 (3) pp. 271-275* 

NOTE: This publication is included on pages 485-489 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

http://dx.doi.org/10.1046/j.1468-1293.2003.00155.x

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