

BETTER MEDICATION  
MANAGEMENT FOR  
ABORIGINAL PEOPLE WITH  
MENTAL HEALTH DISORDERS  
AND THEIR CARERS -

*Final Report 2003*

FINAL REPORT

FINAL  
REPORT  
2003



FLINDERS  
UNIVERSITY  
ADELAIDE  
AUSTRALIA



ABORIGINAL  
DRUG AND ALCOHOL  
COUNCIL (SA) INC

*A collaborative  
project of the  
Flinders University  
School of Nursing  
and Midwifery  
and the Aboriginal  
Drug and Alcohol  
Council (SA) Inc.*

medication  
management  
aboriginal people

# Better medication management for Aboriginal people with mental health disorders and their carers - Final report 2003

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# **Better medication management for Aboriginal people with mental health disorders and their carers. Final report 2003**

*A collaborative project of the Flinders University School of  
Nursing and Midwifery and the Aboriginal Drug and Alcohol  
Council (SA) Inc*

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# Executive summary

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## Introduction

Unrelenting grief and loss, chronic poverty, social dislocation, poor educational opportunities, lack of access to appropriate services, and long term cultural disruption continue to severely impact on the health and wellbeing of all Aboriginal Australians. The latest statistics indicate that the Aboriginal population is still much sicker, younger and poorer than the non-Indigenous population in Australia. Mental health (social and emotional wellbeing) problems are widespread among Aboriginal people, and often complicated by chronic multiple physical illnesses and/or substance misuse, and therefore use of multiple medications. Quality medication management can be difficult for many Aboriginal people, including those with mental health problems, their carers or other family members. Anecdotal evidence suggests that unsafe or inappropriate use of medicines is common, with potentially damaging physical, social and economic consequences. However there has been to date a lack of research evidence to inform policy and practice change to address these issues.

## Aims and objectives

This research project aimed to:

- explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications;
- recommend strategies to improve quality use of medicines by this group, informed by the findings;
- implement and evaluate selected recommendations.

## Methodology

The research was conducted by a partnership of investigators from the Flinders University School of Nursing & Midwifery and the Aboriginal Drug and Alcohol Council (SA) Inc, in collaboration with Aboriginal communities and other stakeholders across South Australia. A participatory action research design was chosen, in keeping with the Indigenous research ethics underpinning the project. The research was conducted in seven urban, rural and remote regions of SA. SA-wide and regional steering committees drawn from participating Aboriginal communities, Aboriginal and mainstream health and related services and other stakeholders guided all aspects of the research. We used multiple research methods, including a review of literature and key documents; semistructured interviews with clients, carers, community leaders and health and other relevant professionals in each region; a statewide survey of service providers; a review of most recent SA hospital separation statistics; and reflection on interventions made in response to findings during the project. The research team and steering committees collaboratively considered the combined findings and

formulated recommendations to improve the safe use and management of medications and related issues for Aboriginal people with mental health problems and their carers/families. Selected strategies were implemented and evaluated. The project was conducted from July 2000 - June 2003.

## **Findings**

The review of literature and key documents considered over 600 items. It revealed many scholarly papers, reports and reviews on Aboriginal health, mental health and substance use, but very little literature on medication management in relation to Aboriginal mental health was identified. The links between social and health inequities are well established, as are the impacts of generations of racist policy and practice on physical and mental health and spiritual, social and emotional wellbeing. We identified a number of plans and recommendations to address these issues, but it appears that few have been implemented or evaluated.

Over 130 people took part in interviews and focus groups. This qualitative information provided a rich insight into the direct experiences and views of Aboriginal people with mental health disorders, their carers and health workers in relation to medication use and associated issues. The findings were remarkably similar in all SA regions in which the research was active. The data confirmed that most Aboriginal people experience social and emotional wellbeing problems, either themselves or as carers of family or community members, and that coping with these problems, including managing medicines safely, is an added burden on already severely disadvantaged people. The data revealed many instances of unsafe medication use among Aboriginal people with mental health problems and their carers, compounded by alcohol and substance misuse, lack of professional support, and lack of access to appropriate services. The data also highlighted the stressors on Aboriginal health services and workforce, lack of Aboriginal and mainstream workforce training on safe medication management and mental health/alcohol and drug issues, serious inadequacies of mainstream health services for Aboriginal people, and institutionalised and individual racism in the community at large. Each of these problems clearly impacts in major, negative ways on safe and effective medication management.

114 service providers took part in a purposive survey to explore their knowledge, understanding and roles in medication management for Aboriginal mental health. Participants were purposively selected workers and managers from a wide range of health and human service organisations from metropolitan, rural and remote SA, and all had some involvement with Aboriginal people with mental health problems and medication. The survey revealed an alarming lack of training about mental health, drug and alcohol, and safe use of medicines. The needs for accessible, relevant, regular and

accredited training courses, and culturally appropriate information and resources were highlighted. The survey also confirmed the wide range of issues that impact on clients' ability to access services and use medicines safely, and workers' ability to deliver services that support quality use of medicines.

SA hospital separation statistics for the 5 years from 1995-2000 were reviewed. In that time there were 8794 hospital separation records of Aboriginal people normally resident in SA who had a primary or other diagnosis of mental health disorder. Most had been diagnosed with a number of chronic or acute physical illnesses as well as their mental health problem. 79% had drug and alcohol problems. An association between mental illness and preventable injury was revealed - about a quarter of records were of people also diagnosed with injury, poisoning or other consequence of an external cause, mostly assault, self-harm, crashes and falls, but rarely adverse effects of medication.

As this was an action research project, and to address aims 2 and 3, the research team worked more closely with some communities who were able to participate to develop, implement and evaluate strategic interventions in response to local findings. These included: workforce and community education; improving access to, and safe management of, medications; coordination of care for Aboriginal people with mental health problems; safe care of intoxicated people; advocating for, and supporting ways to, increase capacity of Aboriginal service providers and communities. Evaluations of these strategic interventions were positive and in many cases the initiatives are ongoing or have led on to related activities. Process evaluations underscore the importance of local partnerships, commitment to sustainable change, and tailoring strategies to meet local needs and contexts. The most pleasing outcome is the improved morale, confidence and knowledge of those involved, especially Aboriginal clients, health workers, substance misuse workers, drivers and carers.

The findings from the separate components of the research project were triangulated and integrated, enhancing the rigour of the research. We are confident of the credibility of the results because of the striking similarity between issues revealed by the various research methods used and the consistency between regions.

## **Recommendations**

It is of great concern that the major problems and issues impacting on safe use of medicines by Aboriginal people with mental health disorders have not been addressed yet, given the many existing guidelines and strategic plans. The failure of the SA Mental Health Service, and other SA and Commonwealth organisations to implement them is unacceptable, as health inequities are being perpetuated, and people's health and wellbeing are put at risk.



The research team, in collaboration with the SA-wide steering committee, developed the following recommendations for improving quality use of medicines for Aboriginal people with mental health problems, their carers and families, based on the combined findings of this project. The challenge for the SA health system is now to operationalise these recommendations, and commit to real, sustainable change to policy and practices that improve the safe use and management of medication among Aboriginal people with mental health problems, their carers and service providers, leading to better health and wellbeing for these vulnerable people.

## **Services**

1. Ensure that all Aboriginal people in SA have ready access to affordable and culturally respectful health, medication and related services.
2. Ensure that all Aboriginal clients have equitable access to subsidies and other supports for their health care and essential medication use wherever they access the health care system.
3. Facilitate access to bona fide traditional healing practitioners and medicines.
4. Organise all health services so that hospital and community pharmacists, registered nurses, medical officers and Aboriginal health workers collectively and separately ensure that all Aboriginal clients and their carers/families receive sufficient time, understandable information and education to make informed decisions about their medication regimes and how to safely manage their medications, at every episode of care.
5. Implement procedures and systems in all services that provide medicines to Aboriginal clients at home/in camps for timely transport, provision, storage and supervision of safe medication use.
6. Actively target Aboriginal and mainstream health services with information about funding opportunities for additional staff, resources and other supports.

## **Coordination of care**

7. Ensure that provision of care is coordinated within and across all health-related systems (ie health, mental health, drug and alcohol, social support and criminal justice systems; mainstream and Aboriginal services; local, regional and metropolitan services; and government and non-government organisations)
8. Integrate mental and general health care for Aboriginal clients and their families at local, regional, rural/remote and metropolitan services.
9. Ensure timely and effective communication between specialist service providers and referring GPs, Aboriginal health services and other primary care providers to ensure continuity of care for Aboriginal people with mental health problems.

10. Implement effective communication systems between key services eg through clearly identified and agreed pathways and protocols of care, memoranda of understanding, joint funding submissions, service agreements, reporting and staff appraisal systems.
11. Encourage uptake of targeted funding schemes to employ well trained and supported Aboriginal health personnel to coordinate and support safe medication management among Aboriginal clients of GPs and Aboriginal health services at the local level.
12. Advocate for and support Aboriginal carers/family members to enable them to accompany and stay with Aboriginal clients when transferred for psychiatric care and other relevant services.
13. Promote the provision of local services rather than centralised services (eg GPs, local mental health and drug and alcohol services, Aboriginal services) to care for Aboriginal clients with mental health and substance use problems, in partnership with carers/family members.
14. Conduct research to evaluate and refine integrated Aboriginal mental health care and medication management systems to inform best practice for local needs and contexts.
15. Provide well-supported and coordinated pathways of care for Aboriginal juvenile and adult offenders with a mental health disorder, and their families, when entering or exiting a correctional facility, and/or on parole, regarding their safe medication management and ongoing mental and general health care.

## **Carers and other family members**

16. Provide for community education activities on the rights and special needs of Aboriginal carers and other family members, and how to access respite services and ongoing resources.
17. Provide effective support mechanisms for Aboriginal carers/family members.
18. Fund and support Aboriginal carer groups in local communities.
19. Promote the provision of locally available services for carers and other family members of Aboriginal people with mental health and substance use problems.

## **Workforce development and education**

20. Provide adequate induction, ongoing training, clear policies, protocols and reporting procedures for safe medication management to all personnel with any role in handling, transporting, storing, providing or assisting in the administration of medications.
21. Provide basic and specialised training for all staff of Aboriginal and mainstream health and related services in mental health, social and emotional wellbeing, drug and alcohol, and cultural safety.

22. Ensure that this training is provided locally, meets the needs of local services and communities, is regularly updated, and articulates with further education pathways.
23. Ensure that safe medication management, mental health and drug and alcohol are included and assessed in core curricula of all relevant Vocational Education and Training (VET) and tertiary education programs, and strive for a nationally consistent approach.
24. Foster and resource networks of workers to ensure information flow, peer support, and sharing of knowledge and skills regarding safe medication management, care of Aboriginal people and families with mental illness and other health problems, and related issues.
25. Build the capacity of the Aboriginal workforce to deliver better health and social services to their community members through improved access to education and employment initiatives.
26. Ensure that all workers, including drivers, of Aboriginal health, substance misuse, mobile assistance and social and emotional well-being programs have a strong network of mentors and peer supports, and safe workplaces, that actively promote mental health and well-being of all employees.

## **Community development**

27. Support Aboriginal communities in their right to self-determination of their own health, including mental health, outcomes and goals.
28. Provide culturally and linguistically appropriate community education and health promotion programs and resources about Aboriginal social and emotional wellbeing, mental health issues, drug and alcohol issues, and safe use of medications, to reduce the shame and ensure that all communities have access to relevant and understandable information and resources.
29. Continue to implement and enhance proactive Aboriginal employment schemes in the wider community, private and public enterprise, to enhance career opportunities and leadership roles, reduce poverty and raise morale.
30. Ensure that all members of Aboriginal communities are well informed about their moral and legal rights to non-racist mental health, drug and alcohol and general health and social services.
31. Ensure that members of all Aboriginal communities understand, have support and can easily access legal and other mechanisms, eg the Equal Opportunity Commission, to report and lodge complaints of racism of any service providers.
32. Ensure that members of all Aboriginal communities understand, have support and can easily access the SA Guardianship Board and Public Advocate regarding their own or family members' mental health issues and related needs.

# Chapter One

## Introduction

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Past and ongoing racist policies and practices have resulted in profound and prolonged grief, disempowerment and social disadvantage for Aboriginal Australians. This has led to widespread social and emotional wellbeing problems, and multiple physical, spiritual and mental health disorders [1-6]. The ongoing burden of living with such complex health problems, or caring for someone with these problems places inordinate strain on the physical and mental health and wellbeing of individuals, and the coping capacity of the Aboriginal community as a whole. Sadly, despite numerous enquiries, reports, recommendations and strategic plans [7-11], Aboriginal Australians are still the sickest and poorest in the nation [3, 12].

Of particular concern is the unrelentingly high prevalence of mental health problems, including drug and alcohol problems, among Aboriginal people. Recent national statistics [3] indicate that compared to non-Indigenous Australians, Aboriginal people are hospitalised more often for mental or behavioural disorders and are twice as likely to die from a mental disorder. Furthermore, Aboriginal people have disproportionately high rates of assault, suicide and incarceration. From an Indigenous perspective, mental health is a socially constructed concept that incorporates the spiritual, social, cultural, and physical dimensions of life, and is intertwined with adverse economic and political conditions [13]. Consequently, to be influential, reports and plans relevant to Aboriginal mental health must prioritise wellness and promote holistic, culturally informed approaches to healing [5, 10, 14-17].

Safe and effective medication use by people with mental health problems and their carers is a major issue, particularly if there are coexisting physical health problems. We define medications broadly to include licit and illicit drugs, prescribed or over-the-counter medicines, alternative and traditional medicines, recreational drugs and alcohol. Social, health and economic issues associated with the use of medications include intoxication, excessive use and dependence, adverse drug reactions, side effects, drug interactions, hospital admissions, accidents and falls, re-incarceration, misdiagnosis or exacerbation of dementia and other conditions, and psychological effects of polypharmacy [18-20]. The combination of prescribed medications, together with other substance use (such as over-the-counter medicines, illicit drugs or alcohol) can compound the physiological, psychological and social problems of mentally ill persons [21]. National policies and strategies for the quality use of medicines have been formulated [22, 23] in consultation with consumers [24], professionals, government and industry. The Commonwealth also funds a range of programs to improve quality use of medications through the Quality Use of Medicines Evaluation Program [25].

There is little research on medication use specific to Aboriginal cultures apart from earlier studies from this research team [18, 26], which show that medication management for Aboriginal persons and their carers is problematic because of: cultural issues; limited access to quality, culturally appropriate medication information and support; sparse economic resources; lack of education; and differences in understanding, personal resources and skills. Other literature has focused on prescribing rates [27], compliance [28], importance of good communication [29, 30], workforce development [31], pharmacy services [32] and integration of services [33, 34]. Although it is agreed that substance misuse and polydrug use have major negative impacts on health [35, 36], there is little evidence of sustained improvement in health outcomes resulting from the programs aimed at addressing these issues among Aboriginal people [35]. No research specific to medication management for Aboriginal mental health has been identified. The lack of literature highlights the need for research to inform policies, health promotion, education and practice guidelines for safe, effective medication management for Aboriginal people with mental illness. This research project - *Better medication management for Aboriginal people with mental health disorders and their carers* - was carried out to help address this need.

*Better medication management for Aboriginal people with mental health disorders and their carers* was funded by the Commonwealth Department of Health and Aging Quality Use of Medicines Program, and was conducted from 2000-2003. An Australian Rotary Health Research Foundation grant funded a pilot study conducted as an adjunct to this project. This comprehensive report brings together all the components of this complex project into one document. Some components have already been published as stand-alone reports [37-39].

This report is set out as follows:

- Executive summary.
- Chapter 1 (Introduction) gives the background to the project and outlines the report.
- Chapter 2 (Aims) lists the aims and objectives of the research.
- Chapter 3 (Methodology) details the action research design and the rationale for using multiple methods and locations, reflects on the effectiveness of the approach, and offers a partnership model for Aboriginal health research.
- Chapter 4 (Literature review) provides an overview of the literature and key documents pertinent to Aboriginal mental health and medication use issues.
- Chapter 5 (Interviews and focus groups) summarises the main findings from interviews and focus groups with Aboriginal people who have mental health problems, carers and family members, and health and welfare professionals who serve them. These interviews

and focus groups were held in 7 different regions of SA. Detailed reports of findings for each region are included in Attachments 1-7.

- Chapter 6 (Survey of service providers) reports on the SA-wide survey of relevant health and social service providers.
- Chapter 7 (Review of hospital separation data) explores the hospitalisation patterns of Aboriginal people with diagnosed mental health disorders, their comorbidities, associated medication, alcohol or other drug problems, and injuries.
- Chapter 8 (Strategic interventions and outcomes) details the many interventions conducted as part of this project and continuing beyond it, such as education and training, advocacy, building partnerships and coordinating care. Evaluations are included where appropriate, and outcomes are highlighted.
- Chapter 9 (Discussion) draws together the major findings from all the different components of this project - literature review, interviews and focus groups, SA-wide survey of service providers, hospital separation statistics and strategic interventions.
- Chapter 10 (Recommendations) lists the recommendations that were formulated collaboratively with the state-wide steering committee, based on this research.
- Attachments 1-7 are the regional reports containing detailed interview/focus group findings including many examples of participants' experiences and feelings in their own words, and locally contextualised interpretations, recommendations and interventions. The regional reports are from Port Augusta, Port Lincoln, Metropolitan Adelaide, Coober Pedy, Maitland, Murray Bridge and Riverland.
- Attachment 8 is the report of the pilot study conducted in Northern Metropolitan Adelaide.

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# Chapter Two

## Aims

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The aims of this research were to:

1. Explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications.
2. Recommend strategies to improve quality use of medicines by this group, informed by the findings, and in collaboration with Aboriginal communities and other stakeholders.
3. Implement and evaluate selected recommendations.

The key objectives were to:

1. Form steering committees made up of representatives from all key Aboriginal groups and other relevant groups in urban, rural and remote regions of South Australia.
2. With advice, guidance and support of the steering committees, identify, approach and successfully engage the key Aboriginal and non-Aboriginal services that would be required to support the activities of the research.
3. Recruit and train Aboriginal research assistants in the skills needed to communicate, contact, recruit, interview, record, assist in data analysis, and respond to specific information and referral needs as these arise.
4. Conduct interviews and focus groups in each region with Aboriginal people who have mental health problems, their carers and other family members, and the health and welfare professionals who serve them, to gain an understanding of their direct experiences, needs and contexts, with particular reference to the use of medications and other substances.
5. Conduct a SA-wide survey of health and social service providers to explore their knowledge, experience and training needs in relation to safe use of medication for Aboriginal people with mental health problems.
6. Review the published literature and other key documents relevant to safe use of medication by Aboriginal people with mental health problems.
7. Review recent hospital separation data of SA Aboriginal people with diagnosed mental health disorders in relation to medication, alcohol or other drug problems, comorbidities and injury.
8. Based on the research findings, collaboratively develop recommendations to improve policy and practice impacting on

medication management by mentally ill Aboriginal people, their carers and other family members.

9. Implement key recommended changes to policies and practices in selected SA regions collaboratively, and as needs and opportunities arise.
10. Evaluate the efficacy of these changes to policies and practices, and identify barriers and opportunities for achieving change to policy and practice.
11. Develop comprehensive reports on the research findings and distribute these to all relevant bodies in the Aboriginal community and their service providers, and the wider academic and health service sectors.

# Chapter Three

## Methodology

---

### **This chapter was prepared by:**

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This chapter begins with some considerations about Indigenous research in general that were influential in our approach to the research, including choice of project design and procedures. Following a description of the design, some very important ethical considerations are addressed, including the ethical guidelines and obligations governing our conduct as researchers, after which a brief overview is given of the methods used for data collection and analysis. The chapter continues with a discussion of several methodological issues arising from the project, and concludes by summarising a partnership model for ethical Indigenous research that we believe can produce tangible benefits for participating communities.

### **Introduction**

Indigenous research in Australia has a troubled history. In many respects it parallels the history of Indigenous health in Australia already described in this report - a history shaped by oppressive policies of colonisation, racism, disregard for social and emotional wellbeing, and inadequate funding. As Holmes and her Aboriginal co-researchers stated, 'Australian Aboriginal people and their organisations have had reason to be suspicious of research, which has often been conducted without their consent or involvement' [1](p.1267). Anthropologists were the first to observe and subsequently represent Aboriginal culture, drawing conclusions about 'primitive' intelligence, followed by medical researchers focusing on prevalence studies - experienced by Aboriginal people, not surprisingly, as 'another form of exploitation' [1](p.1268).

Examples of contemporary authors who, over time, have highlighted the importance of respect for the rights of Indigenous people and communities in the research process can be found readily [2-12]. These authors consider lack of respect has been a major problem in the past and they offer many ideas and strategies to ensure due respect is integral to all future research. Hunter [13] has usefully outlined the major developments over time in this regard, pointing firstly to the 1970s as a decade of significant change, with the 'charged political atmosphere' drawing attention to Aboriginal social disadvantage. Nevertheless, researchers often did not engage with those they

researched beyond 'providing a copy of the final report to "some-one" in the community' [13]. The 1980s saw the increasing presence of Indigenous professionals and research linking disadvantage with persistent poor health. Indigenous people were involved in the research 'but still often in liaison or "consultation" roles' [13].

In the 1990s, significant strides were made, with Indigenous organisations and communities taking responsibility for commissioning and conducting research. Hunter reported that researchers had to relate to:

*... increasingly sophisticated Indigenous steering committees and organisation boards who not only reviewed propositions but set the research priorities and agendas* [13](p.7).

Aboriginal communities were interested in research that led to results and could be evaluated. Enduring connections between researchers and Indigenous communities were established and researchers were increasingly involved in the implementation of interventions flowing from the research [13].

In 2001 Hunter [13] foresaw that Indigenous health research would continue to evolve. He believed it was likely to be increasingly localised and responsive to particular community needs, and that researchers would increasingly be Indigenous. Significantly for this project, Hunter considered Indigenous health research was:

*... likely to be solution-focused action research, dynamically responding to circumstances rather than seeking to control them, and informing change and solutions as part of the research itself* [13](p.7).

Despite the increasingly positive trends in Indigenous research practices over time, as outlined above, we were mindful of challenges cited recently by other authors. For example, Holmes *et al.* [1] reminded readers that scope exists for research in Aboriginal communities to be either harmful or beneficial. They state (with substantiation) that there are likely to be 'practical and logistical difficulties, arising from different priorities and cultural attitudes', and further, that research in Aboriginal communities is not 'simply a matter of non-Aboriginal researchers applying standard methodologies, but with cultural sensitivity' [1](p.1268).

We noted that others held similar views about non-Aboriginal researchers. For example, Tsey (reporting on a consultative process regarding a cooperative research centre in the Northern Territory) stated that a major concern was that the centre:

*...did not become yet another avenue for non Indigenous researchers to further their academic ambitions at the expense of Indigenous people* [14](p.21).

She reported her Indigenous respondents as saying they:

*...wanted to participate as principal researchers in their own right and not just as research assistants and other support workers (p.21).*

On the related point about not applying standard research methodologies, Holmes *et al.* believe new research approaches are needed for Aboriginal research and that their research has contributed to the elaboration of a combined qualitative and quantitative approach [1].

A recently released (2003) series of monographs by the Cooperative Research Centre for Aboriginal & Tropical Health (CRCATH) provides a timely overview of the history of Indigenous health research, including its poor track record. The series specifically addresses a proposed agenda of reform that incorporates rethinking Indigenous research methodologies, the role of institutions in the reform process, and improved promotion of the use of Indigenous health research. We found this series from CRCATH exemplified a positive and comprehensive view of the future that could be highly beneficial to Indigenous communities and health researchers [2, 3, 15, 16].

## Choice of study design

Our choice of study design was influenced in part by earlier research of older Aboriginal women and their medication experiences [17, 18], in which the special nature and concerns of Indigenous research were recognised. In this research we were committed from the outset to culturally respectful, ethically responsible research that was outcome-focused, not just curiosity driven. We required a design that would enable us to go beyond making recommendations to actually developing local strategies with communities that addressed their particular needs and priorities, and implementing and evaluating these. The design had to be flexible, pragmatic and participatory - that is, participants needed to play an active part in all stages of the research process.

Participatory action research was chosen as the preferred design because its style is participatory and democratic (participants and researchers are regarded as equal), and it contributes to social change (focuses on generating solutions to practical problems) [19]. It typically draws on qualitative methods but is not restricted to these. Action research has been strongly endorsed as suitable to both health research [19] and Indigenous research [15, 20, 21]. As one Indigenous researcher, who believes this is the pre-eminent Indigenous research method, stated:

*Empowerment and self-determination are basic Indigenous aspirations. Participatory action research creates opportunities for these aspirations to be met. ...Fundamental to participatory action research is control and ownership over the process by those who are its focus [20](p.13).*

Action research 'entails collaborative spirals of planning, acting, observing, reflecting, and re-planning' [19], and as such is highly interactive and action oriented. It is not without problems however. For example, Henry *et al.* [15](pp 9-10) highlight critiques in which the flow of empowering consequences to marginalised and minority Aboriginal communities is questionable. They also point out that the negotiation involved makes it 'a long and complicated process'.

Importantly, action research enabled us to employ triangulation - using multiple data gathering methods (interview, survey, focus groups, statistics analysis) to gain different perspectives and understandings of the topic from various participant groups and individuals (clients, service providers, researchers), and to draw all these together to produce a comprehensive and credible picture. The design allowed us to work simultaneously in multiple urban, rural and remote locations, generating local solutions for local issues, but also feeding into a South Australian-wide (SA-wide) report with overarching recommendations.

## **Ethical considerations**

Ethical considerations are of major concern in Indigenous research. It is said Indigenous peoples are the 'most researched people in the world' and that for over two hundred years Indigenous Australians have been subjected to 'undisciplined research and analysis' [22](p.13). There have been major developments in Australia marking a move from undisciplined to disciplined Indigenous research, including the development of ethical codes of practice and key refereed literature available for intending researchers, as outlined helpfully by Bourke [12].

We were mindful from the outset to fulfil certain obligations to respect cultural practices, such as those outlined by Smallacombe [22](pp18-20):

- obligations associated with kin relationships; for example, required presence at funerals;
- the importance of Elders and community organisations in community life;
- the need for extended timeframes in which decisions are made and the collective nature of those decisions;
- understanding the cultural system of collective responsibility for social action;
- awareness for Indigenous languages and Indigenous ways of communicating;
- respect for the concept of "women's business" and "men's business" and embargoes placed on using names and photographs of deceased persons. Also, not using highly offensive terms such as "half-caste" or "full-blood";
- understanding that Indigenous communities are diverse - being accepted in one community does not necessarily mean acceptance into another.

Also, understanding that naming (bestowal of a name that gives reality to an intruder) is context specific and should not be used beyond this geographic or group context.

Specifically, in this project we conformed with the National Health & Medical Research Council (NH&MRC) guidelines [23] arising from a national conference in 1986, stating that research on, or about, Aboriginal people or Aboriginal issues should:

- be conducted for, with or by, Aboriginal individuals, groups and/or communities;
- arise from perceived Aboriginal needs;
- be non invasive, understandable and culturally acceptable;
- have Aboriginal approval;
- return some benefit to the community;
- have Aboriginal approval to publish outcomes.

In following these guidelines, we discussed at length the project and issues arising from it within the team with Aboriginal communities, and at statewide and local steering committees. If local community members wanted more stringent controls than those specified by the three relevant ethics committees, we complied. For example, we worked with an Aboriginal community controlled organisation to develop a culturally acceptable protocol for handling and storage of audiotapes and other data. Throughout the project, participants' welfare took precedence over research aims - that is, the needs of the community and individual participants were always considered more important than the project.

All interview and focus group participants were fully informed by a member of the research team about the aims, process and expected outcomes of the research, and were asked for informed consent that was recorded verbally or in writing according to the circumstances. All participants were interviewed in a culturally safe way in the manner, place and time of their choice. Aboriginal research assistants recommended by local steering committees conducted most of the interviews. All participants were reminded that they could cease the interview and their involvement in the research at any time. No personal identification was recorded, and cultural practices were respected at all times. All participants could be accompanied by family members or others, according to their needs and wishes. All data are stored in accordance with NH&MRC ethical guidelines in a locked cabinet and will be stored in this manner for seven years. The interview guides, participant information sheets and consent forms are attached to Chapter 5.

Handling of audiotapes and transcripts was strictly controlled. Data were not transmitted by email at any stage, only registered mail was used when



required and professional transcribers of tapes were not named or linked to individual tapes. The culturally acceptable protocol for handling and storage of audiotapes and other data developed for this project is now accepted as best practice by colleagues. An unanticipated outcome was the need for confidential debriefing of transcribers emotionally distressed by the content of some tapes, compounded by the need to listen over and over to capture accurate wording.

The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggoorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of South Australia. The research was also deemed appropriate by each of the local host Aboriginal health services with which we worked.

## **Steering committees**

Local project steering committees were convened to oversee and guide all aspects of the project in each region. Members were local health and social service providers from Aboriginal and mainstream organisations, the researchers and Aboriginal community members (listed in the local project reports). Each local steering committee was invited to advise on:

- ethical and practical issues regarding data ownership and security;
- recruitment and training of Aboriginal research assistants acceptable to local Aboriginal communities;
- engaging potential community participants;
- relevant local and regional issues and events;
- following up on issues raised by local Aboriginal research assistants on behalf of anonymous interview participants;
- drafting local reports and formulating recommendations; and
- implementing and evaluating selected local strategies based on the recommendations.

Local steering committees met with the research team as needed, generally in the premises of the Aboriginal health services that hosted the project in each region.

A SA-wide steering committee was also convened to guide the project as a whole. It comprised representatives of key Aboriginal and mainstream health and social service sectors, the research team, a member of each local steering committee, other stakeholders and co-opted members with specific expertise or influence (a list of SA-wide steering committee members and their affiliations is attached to this chapter). The Statewide steering committee was invited to advise on:

- ethical and practical issues regarding data ownership and security;
- drafting and piloting the research instruments (for example, interview guide, survey questions);
- the findings of all components of the project; and
- drafting statewide recommendations.

## **Data collection and analysis**

Data were collected and analysed via multiple methods:

- review of literature and key documents (Chapter 4);
- semi-structured interviews and focus groups with Aboriginal people with mental health problems, their carers/family members and workers who provide their health and related services (conducted in multiple locations, see attachments 1-7 for the regional reports, two of which have also been published as stand-alone reports [24, 25], and the summary of interview/focus groups in Chapter 5);
- SA-wide survey of service providers (Chapter 6, also published as a stand-alone report) [26];
- analysis of recent South Australian hospital separation data for Aboriginal people diagnosed with mental health disorders (Chapter 7);
- feedback on effect of implementing selected strategies and preliminary outcome/process evaluation results (conducted in multiple locations, see attachments 1-7 for the regional reports, two of which have also been published as stand-alone reports [24, 25], and the summary of strategic interventions and outcomes in Chapter 8).

Detailed data collection and analysis methods are included in other chapters of this report, as indicated above, and will not be reiterated here.

Recommendations for improving quality use of medications and related issues for Aboriginal people with social and emotional wellbeing problems were developed, informed by the findings of the interviews and focus groups in the regions, the survey, the literature/document review and the review of health statistics. The research team, steering committees, Aboriginal health workers, service providers, social and emotional wellbeing and substance misuse workers, and other key stakeholders worked collaboratively to arrive at these recommendations.

## **Some methodological issues**

It would be simplistic and misleading to suggest this project was accomplished without difficulty. Albeit aware of cautions cited in the literature by other researchers, we ventured into the project with high

enthusiasm and expectation that the carefully prepared proposal could be executed as planned. Indeed much was accomplished as planned, however most of the time this was possible only by continual and creative rethinking and re-planning (testing the strengths of action research to the limit), flexibility, dogged perseverance and ongoing renewal of our commitment as a research team to the project aims. We certainly emerged as stronger and better researchers, with good ideas and advice to others who may follow us in the field of Indigenous health research. Some key issues that engaged and challenged us in the research process are now described.

### **Navigating the bureaucratic maze**

We were shocked to discover the extent of confusion and uncertainty among service providers and carers about funding systems for Indigenous health and how these affected available services and supports. Also evident was a lack of knowledge about the various government and non-government organisations at local, state and national levels that could assist Aboriginal clients, carers and workers, and uncertainty about the roles and responsibilities of these organisations. This was not a reflection upon the individuals concerned - we were equally confused. Despite warnings in the literature, we were ill-prepared for the dozens of relevant research reports and their multiple recommendations concerning Indigenous health, often overlapping in time, place and intent, and without clear indication as to impact. We found the confusion directly affected service provision - workers at all levels were wasting time and resources navigating the maze of information and bureaucratic guidelines available. To confound matters it appeared information and guidelines were also regularly changing. It was not unusual to be assured one day or week (for example by an experienced service provider) we were in possession of all relevant information, and the next day or week to have yet another, sometimes major report put before us. Therefore our review of literature and key documents (Chapter 4) cannot claim to be comprehensive, despite taking exhaustive measures to locate everything possible, but nevertheless it served as a rich source of information in which to locate the study.

### **Recruitment and training of Aboriginal research assistants**

The very laudable plan to employ and train local Aboriginal research assistants within the scope of the project proved, in the main, overly ambitious. The challenges faced by the research team in securing suitable Aboriginal research assistants and arranging for their training were considerable. Making connections (following up suggested persons and making contact), establishing rapport, ascertaining suitability, negotiating family and other cultural issues, organising and often conducting training,

maintaining individuals' interest in the task at hand, and arranging for the interviews to take place all took many, many hours of dedicated effort, mostly in remote locations. Our success rate was variable across locations. Some Aboriginal research assistants enjoyed the work and were able to make an outstanding contribution, while others did not enjoy or complete their work for various reasons.

A closely related issue was inter-family and inter-community confidentiality. This emerged as a major factor for all members of the research team as we sought to secure research participants and data for the project. Despite the greatest care and commitment in ensuring anonymity and confidentiality, individuals were often reluctant to speak freely because of family and community connections, rivalries and sensitivities. We also found team members' Aboriginality could be an advantage or disadvantage at times, confirming our approach of a culturally mixed team.

## **Leadership and research team issues**

Success of the project was always dependent on the researchers pulling together as a team, with equal commitment and effort to achieve the project aims. (We wished to exemplify the State Strategy and Action Plan 'partnership approach' [27] in action!) This required close and genuine collaboration between Aboriginal and non-Aboriginal research team members, who came from both higher education (Flinders University School of Nursing & Midwifery) and non-government, community controlled (Aboriginal Drug and Alcohol Council) sectors. The complexities and sensitivities of bringing this collaboration about are beyond adequate expression here. We believe, however, the very different work cultures of university and non-government services (layered upon other cultural factors) played a part. On reflection, it may have been naive of us as a team to believe we could fully achieve the degree of collaboration required. As a microcosm of the larger, problematic scenario of Indigenous health and research, how could we expect our team not to experience some limitations and barriers to success?

In brief, two Aboriginal research coordinators left the project during implementation, requiring major reorganisation. Questions were raised but never finally resolved, about who were the 'principal' researchers on the team. Misunderstandings persisted about the roles and responsibilities of different team members, as both the composition of the research team and the roles of members changed over the life of the project. The commitment and research effort of the team members varied markedly, and some research tasks were out-sourced to other experienced researchers by necessity as a result of these problems.

In highlighting these team difficulties, we wish to state the experience was also one of the most rewarding of our professional lives. The extent and depth of our efforts to work productively together, friendships forged and lessons learned will remain invaluable. As indicated earlier, we are better researchers for the experience and wish to document our approach for the potential benefit of others. In particular, the nature of our research team allowed us to forge increasingly close and ongoing relationships with many Aboriginal colleagues and community groups.

## **Partnership model for ethical Indigenous research**

The research methodology is summarised here by way of a model titled 'Partnership model for ethical Indigenous research'. The model reflects the four key features, or corner stones of our research:

- Respect;
- Collaboration;
- Active participation; and
- Meeting needs.

In describing this model, we do not claim its features to be original (they can all be found in the literature to some extent). However, we believe the way we integrated them to work for us in practice is original. That the model worked effectively is evidenced by positive project outcomes and ongoing developments generated by the research. The success of our approach is especially evidenced by our work in Port Lincoln (see Port Lincoln report in Attachment 2), which served as an exemplar for the further detail and schematic representation (Diagram 1).

### **Respect**

Fundamental to the success of the research in all settings was an understanding of, and genuine respect for the historical context of Indigenous health and research in Australia. This understanding and respect extended to the impact of the wider context on current health needs of individual Aboriginal people and how the research project might impinge on their Indigenous rights. We were especially mindful that our particular research interest (medication management for Aboriginal people with social and emotional wellbeing problems) embraced very personal issues that Aboriginal people had quite likely never spoken about openly before. Our respect was expressed by way of the ethical principles we established and endeavoured to uphold throughout the project. Respect between all players (researchers, advisers, service providers and community members) was increasingly reciprocal as the research progressed and is reflected in ongoing relationships and initiatives in train beyond the timeframe of the project.

Mutual respect proved to be a great facilitator. When progress slowed or hurdles presented, it was often our basic positive regard for one another and acceptance of our differing roles and cultural influences that enabled us to find a way forward.

## **Collaboration**

Working together to achieve mutually agreed goals required intense and sustained communication between many parties at state, local and individual levels, often occurring simultaneously and in different locations. The complexity of the collaborative process undertaken is appreciated when one considers:

- the diversity of collaborators (researchers, advisers, service providers and community members);
- the interplay of communication methods used (verbal, electronic, written, face-to-face, telephone, formal, informal etc); and
- the range of issues addressed (all facets of the research process, including problem identification, ad hoc advocacy, data gathering and analysis, reporting and implementation of strategies).

We credit the success of our collaboration primarily to earned trust (based on mutual respect) and shared commitment to the overall research aim (improved Aboriginal health). Preparedness by the research team to spend considerable time and energy in discussions, visits, advocacy, and joint decision-making was also very important, as was diligent attention to communication and being reliable and trustworthy. A key feature of our collaboration was that it involved both Aboriginal and non-Aboriginal individuals at all levels, including the research team, advisory committees and service providers. While the prime beneficiaries of the research were intended to be Aboriginal people, other key players were intentionally both Aboriginal and non-Aboriginal. In establishing and maintaining collaborative relationships, we wished to draw on the widest possible range of experiences, knowledge and abilities, and to strengthen networks and partnerships for the future benefit of the community.

## **Participation**

We were firmly resolved that all project participants would be participate actively and genuinely - not in a superficial or 'token' way as has been the criticism of much Indigenous research. Participatory action research provided the most appropriate research design to achieve this goal. We recognised that action research:

- enabled triangulation of methods;
- emphasised equality and democracy;
- facilitated empowerment and practical outcomes;

- progressed in creative cycles of planning, action and re-planning;
- privileged Aboriginal voices, experience and knowledge, and was endorsed by Aboriginal communities.

An action research approach encouraged and facilitated active participation by all participants. Full and free involvement was encouraged with every effort taken to accommodate individual and cultural factors, for example in relation to the choice of interviewer, those present at the interview, the time and place of interview, sensitivity to issues raised during the interview and post interview follow-up as appropriate. Flexibility with regard to timelines, and working at the pace and convenience of Aboriginal community partners, rather than working to suit the researchers, also enhanced collaborative relationships. Finally, prioritising the participants' needs above the research demands when necessary was also helpful (e.g. there were many occasions when researchers advocated for clients or followed up on issues that emerged during data collection). This active participation was supported and sustained by mutual respect and collaboration - two key features of the model already discussed.

## Meeting needs

It was of paramount concern that the project resulted in sustained benefit to the Aboriginal communities involved. We were resolute in not perpetuating a major flaw of much Indigenous research - making recommendations without any follow-up as to their implementation or impact. It required a concerted effort to establish with key players that this would in fact be the case, as many had experienced researchers entering and leaving their communities without any tangible benefits to those participating. To ensure the research proceeded beyond the recommendation stage:

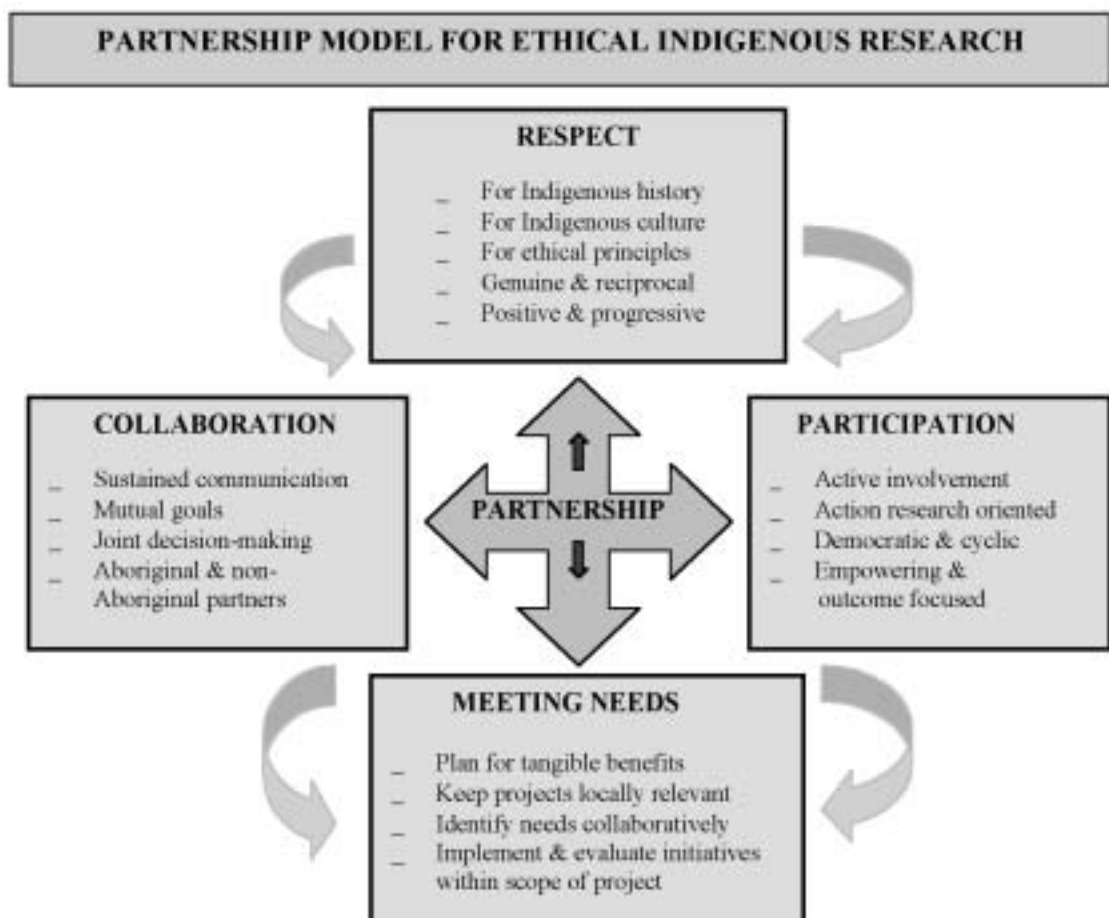
- original proposals included plans for the implementation of selected findings;
- projects were situated locally within communities to ensure relevance;
- data were analysed and urgent needs identified in collaboration with key players, including researchers, advisers, service providers and community members;
- initiatives for meeting needs were mounted in collaboration with key players; and
- evaluation strategies were incorporated to judge the success of initiatives.

Examples of initiatives implemented and evaluated within the scope of the project included: cultural awareness programs; employment of Aboriginal project officers; development of protocols for best practice; in-service education for Aboriginal health workers and carers; securing seed funds for ongoing research; workshops for service providers; establishment of data

bases to aid the work of carers; advocacy; and negotiation and political lobbying to secure improved health care services for Aboriginal people with mental health and medication problems.

Methodologically, these four principal features enabled us to achieve our research aims. In practice, they were necessarily intertwined and highly interdependent. They are teased apart here to indicate the rigour of the multiple research methods employed and thus make credible the research conclusions (rigour is further addressed in later chapters). By laying this 'audit trail' for readers to follow, the reliability and validity of the research is enhanced.

**Diagram 1. Schematic representation of major concepts and their integration in practice**





## SA-wide steering committee

The SA-wide steering committee members are listed below. Many of these people changed their roles during the project and are therefore listed with more than one affiliation. A wide range of relevant organisations is represented (sometimes by more than one person when original members changed roles or were unavailable for meetings). Not all members attended formal steering committee meetings but all were sent information regularly, contacted by telephone and email, and invited to comment on draft reports and help formulate recommendations.

Ms Jacqueline Ah Kit	Director, Port Lincoln Aboriginal Health Service Inc.
Ms Allison Ashman	State Director, Pharmaceutical Society of Australia Inc. (SA Branch)
Dr Michael Baigent	Psychiatrist, Department of Psychiatry, Flinders University
Mr Tony Barrett	Chief Executive Officer, Kainggi Yuntu Warrin Berri
Mr Troy Bond	Project Officer, Drug & Alcohol Services Council
Dr John Bouilly	General Practitioner Port Augusta
	Program Planner, Umoona Tjutagku Health Services, Coober Pedy
Mr Darren Bowd	Aboriginal Services Division, Department of Human Services
Ms Janice Braun	Director, Umoona Tjutagku Health Services, Coober Pedy
Mrs Jenny Briggs	Alzheimer's Association (SA) Inc.
Ms Vicki Brown	Aboriginal Services Division, Department of Human Services
Mr Gary Burgoyne	Aboriginal Research Assistant, Port Lincoln Aboriginal Health Service
Ms Anne Caponi	Pika Wiya Health Service
Mr Anthony Carter	Office of Aboriginal & Torres Strait Islander Health
Dr Peter Chapman	Chief Medical Advisor, Social Justice and Country Services, Department of Human Services
Mr Alwin Chong	Project Officer, Aboriginal Health Council
Mr David Cosh	Pharmaceutical Society of Australia Inc. (SA Branch)
Ms Sharon Cruise	Chairman Ethics Committee, Aboriginal Health Council
	Project Coordinator, QUMEP and Rotary Project
	Manager, Aboriginal Research Forum, Flinders Institute for Health Research
	Project Officer, Drug & Alcohol Services Council
Dr Lynette Cusack	Director of Intervention Services/ Director of Nursing Drug & Alcohol Services Council
Mr Ray Davies	Chief Executive Officer, Port Lincoln Aboriginal Health Service
Ms Anita De Bellis	Lecturer School of Nursing & Midwifery, Flinders University
Dr Charlotte de Crespigny	Professor of Nursing (Alcohol and Other Drugs) School of Nursing and Midwifery Flinders University
Ms Zell Dodd	Office of the Ageing
	Senior Project Officer, Community Development and Primary Care, Department of Human Services
Dr William Donahue	Rural Educator, at the Hepatitis C Council
	Project Officer, C Clearly Program, University of Adelaide
Mr David Egege	Principal Consultant, Mental Health Unit, Department of Human Services
Ms Robyn Fanning	Office of Aboriginal & Torres Strait Islander Health
Ms Margaret Farr	Senior Project Officer, Mental Health Unit, Department of Human Services
Ms Sue Foster	Director of Country Services, Department of Human Services
Mr Andrew Gardner	SA Mental Health Services, Department of Human Services
Ms Vicki Gould	Team Leader Social and Emotional Well Being Team, Port Lincoln Aboriginal Health Service Inc.
Mr Des Graham	Director, Clinical Reform, Mental Health Service, Department of Human Services
Ms Liz Green	Community Health Nurse, Burdekin Clinic
Ms Janine Haynes	Council of Elders (SA) Inc.
Ms Bronwyn Hendry	Country Service, Department of Human Services
Ms Libby Hotham	Pharmacist lecturer, TAFE
	National Centre for Education and Training on Addiction, Flinders University
	Quality Use of Medicines and Pharmacy Research Centre, University of South Australia

	Quality Use of Medicines and Pharmacy Research Centre, University of South Australia
Ms Rosie Howson	Nunkuwarrin Yunti
Mr Grant Kadarchi	President, Pharmaceutical Society of Australia Inc. (SA Branch)
Dr Inge Kowanko	Senior Research Fellow, School of Nursing and Midwifery, Flinders University
Ms Helena Kyriazopoulos	Alzheimer's Association (SA) Inc.
Ms Pauline Lewis	Aboriginal Research Assistant, Coober Pedy
Mr Andrew Lohmeyer	Aboriginal Drug and Alcohol Council (SA) Inc.
Ms Fran Lovell	Office of Aboriginal & Torres Strait Islander Health
Mr Michael McCabe	Nunkuwarrin Yunti
Mr Warren Milera	Aboriginal Liaison Officer, AUSEINET, Southern CAMHS
Mr Rimako Minniti	Psychologist, Drug & Alcohol Services Council
Ms Isabelle Norville	Chairperson, Aboriginal Drug and Alcohol Council (SA) Inc.
Mr Lindsay Osborne	Clinical Team Leader, Nunkuwarrin Yunti, Adelaide SA
Mr Warren Purfoot	Education Manager, Aboriginal Drug and Alcohol Council (SA) Inc.
Mr Geoff Roberts	Aboriginal Health Worker, Northern Metropolitan Community Health Service
	Research Assistant, Rotary Project
	Project Officer, Aboriginal Drug and Alcohol Council (SA) Inc.
Dr Libby Roughead	Research Fellow, Lecturer in Pharmacy Practice, University of South Australia
Ms Cheryl Sanderson	Research Assistant, Flinders University
Mr Alan Scarborough	Rural and Remote, DON, Glenside Hospital
Mr Cephus Stanely	Chief Executive Officer Pika Wiya Health Service
Ms Polly Summer Dodd	Chief Executive Officer, Nunkuwarrin Yunti
Mr Harry Stewart	Office of Aboriginal & Torres Strait Islander Health
Ms Maxine Turner	Council on the Ageing
Mr Michael Turner	Project Coordinator, QUMEP
Ms Anne Vanajeck	Chief Executive Officer, Umooma Tjatagku Health Service
Ms Deb Walker	Team Leader, Muna Paiendi, Northern Metropolitan Community Health Service
	Kalparin Inc., Murray Bridge
Mr Geoff Walsh	Pharmaceutical Society of Australia Inc. (SA Branch)
Ms Glennis Warrior	Acting Team Leader, Muna Paiendi, Northern Metropolitan Community Health Service
Mr Scott Wilson	State Director, Aboriginal Drug and Alcohol Council (SA) Inc.

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# Chapter Four

## Literature Review

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### **This chapter was prepared by:**

- Carolyn Emden
- Inge Kowanko
- Charlotte de Crespigny

This review begins by highlighting some views, findings and developments in relation to the general health and wellbeing of Aboriginal Australians. Perspectives on the mental health of Aboriginal Australians follow. Finally, and more specifically, medication management for Aboriginal people with mental health disorders is addressed. As such, the review locates the research within a wide context of relevance and informs the research problem from multiple perspectives. The review is necessarily selective (with an emphasis on recent reports and publications) and it is expected readers will enrich their understanding of the topic with additional literature of their own choosing. As presented, the review reveals a marked gap in knowledge about medication use by Aboriginal people with mental health disorders.

*Note: the terms 'Indigenous Australians' and 'Aboriginal Australians' are used interchangeably and neither term distinguishes between mainland Aboriginal and Torres Strait Islander people. While the word 'Indigenous' is capitalised inconsistently in the literature, we have chosen to use a capitalised form throughout, unless quoted otherwise.*

## **General health and wellbeing of Aboriginal Australians**

### **Acknowledging the past**

Critiques of Aboriginal health research being inappropriately conducted from 'scientific' perspectives[1] resonate with the views of Ngiare Brown, Indigenous Health Advisor to the Australian Medical Association [2]. Brown states she is often asked how the long-standing problems of Aboriginal people can be overcome, to which she replies it is of central importance:

*...to have an insight into our history and an understanding of our holistic view of health, life and community - a concept of our deep spirituality, our origins, our kinship and social parameters (p.221).*

She believes few people are aware of the history of Aboriginal Australia:  
*more than 200 years of dispossession, oppression, removal from lands  
and family, the diminishment of cultural identity, and the cycle of  
poverty (p. 221).*

Brown has outlined in her paper the major events of these years, culminating in an 'appalling' health status among Indigenous communities. She cited long-term grief and anxiety arising from the Assimilation Policy (whereby Aboriginal children were removed from their families) as being 'significant contributors to the current social, emotional and physical problems' of Aboriginal people. Brown has called for researchers and others to 'acknowledge the legacy of our black and white history'.

In another historical account, Basil Hetzel highlights three 'ecosystems' to which Indigenous people have been exposed - hunter-gather; agriculture; mixed sedentary and nomadic way of life - and their negative social and health outcomes [3]. Hetzel points out that the life expectancy of Australian Indigenous people compares unfavourably with rates achieved by other Indigenous peoples, such as the New Zealand Maori and American Indian populations. This fact receives periodic attention [4] with a recent Aboriginal and Torres Strait Islander Commission (ATSIC) media release claiming the life expectancy gap of Indigenous and non-Indigenous people in the United States had closed to 'about 2 years', while the gap in Australia is 'twenty years...and rising' [5]. The poor health status of Aboriginal Australians has been termed a 'national embarrassment' for Australian society as a whole [6] and a 'damning indictment' on, and collective moral responsibility of all Australians - indeed a 'moral imperative' [7]. Such position statements, combined with a United Nations expert committee expressing 'deep concern' about the position of Indigenous Australians [8] serve to convey a sense of urgency in the literature for positive change in the health and welfare of Aboriginal people.

## Some facts

The ABS two-yearly series, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples* [9], provided the following information in its 2001 third edition:

- Based on the 1996 Census, approximately 2% of the total population of Australia is Indigenous. This is a 33% increase since the 1991 Census, explained only in part by 'natural' increase. It appears increasing numbers of people are identifying themselves as Indigenous, which, as the ABS cautions, makes reliable population estimates and subsequent incidence and prevalence rates for specific diseases difficult.
- In 1996, more than half of all Indigenous people lived in New South Wales and Queensland, with most living in urban areas. Northern

Territory had the highest proportion (28%) of Indigenous people, 20% of whom reported living in 'very remote' areas, compared to 1% of the non-Indigenous population.

- In 1996, Indigenous people 'experienced lower incomes than the non-Indigenous population, higher rates of unemployment, poorer educational outcomes and lower rates of home ownership, all of which can impact upon a person's health and wellbeing.'
- In 1998-99, for each dollar spent on health services for the general population, \$1.22 was spent on health services for Indigenous people. Despite this, Indigenous people accessed health services less than the general population.
- Between 1997-99, the life expectancy for an Indigenous male was 56 years (compared to 76 years in the total Australian population) and 63 years for an Indigenous female (compared to 82 years in the total Australian population).
- The leading causes of death for all Australians (Indigenous and non-Indigenous) for the period 1997-99 were diseases of the circulatory system, cancer and external causes, however Indigenous Australians die at a greater rate and at younger ages than the general population. In Indigenous people, 7-9 times more deaths than expected occurred from endocrine and metabolic diseases, with 88% relating to diabetes.
- Data for 1996-98 showed Indigenous women gave birth at younger ages than non-Indigenous women, with these babies being nearly twice as likely as those of non-Indigenous women to be of low birth weight and twice as likely to die at birth or soon after.
- In 1998-99, Indigenous Australians were more likely to be hospitalised than the general population, with 'care involving dialysis' being the main reason. Diabetes was of particular importance. There were 10-15 times more hospital separations for treatment of Type 2 diabetes than expected for the general population. It was also estimated 50% of the Aboriginal population with the disease are unaware of their condition. Aboriginal people also suffer from the numerous severe diseases associated with diabetes, including cardiovascular and kidney disease, nerve and eye damage, and ulceration and gangrene (pp.1-6).

The Co-operative Research Centre for Aboriginal and Tropical Health has produced a new Atlas of Health-Related Infrastructure for ATSIC [10]. It is claimed to be the most comprehensive study of its kind ever undertaken of Australia's 1200 discrete Indigenous communities and highlights the importance of linking health outcomes to infrastructure. Issues highlighted include:

- an estimated 13 per cent of people in remote communities live in temporary dwellings;
- 57 communities experienced 20 or more power interruptions in the year before the survey;

- 84 communities had no public phones;
- 316 permanent dwellings across 94 communities were not connected to water; and
- 136 communities were more than 100 km from the nearest primary school and 188 were more than 100 km from a health centre.

These infrastructure findings bear out Australian Bureau of Statistics [11, 12] data that clearly show Indigenous Australians are disadvantaged relative to other Australians with respect to housing, living conditions, access to health and educational services, and transportation. Further, '(t)hese disadvantages place them at greater risk of ill health and reduced wellbeing'.

## Transitions to better health

Health gains for Aboriginal Australians over the last 20-30 years include reductions in child mortality, reduced prevalence of communicable diseases, and increased life expectancy yet chronic disease and injury rates continue to increase [13]. In 2001 the National Aboriginal and Torres Strait Islander Health Council laid out a comprehensive health strategy involving setting up numerous Aboriginal controlled health services for implementation over the next decade. The strategy builds on many earlier initiatives at State and Territory level and has as its single goal:

*To ensure that Aboriginal and Torres Strait Islander peoples enjoy a long and healthy life enriched by a strong living culture, dignity and justice.*

The strategy has five aims: increased life expectancy; decreased mortality rates in the first year of life; decreased all-cause mortality across all ages; reduced impact of chronic and communicable disease; and enhanced social and emotional wellbeing [13].

Nine 'key result areas' are articulated in the above National Health Council strategy [13]. These focus upon:

1. *strategic actions to improve coordination between health programs and services*
2. *increased capacity to meet the health needs of Aboriginal Australians by improved training of Aboriginal and non-Aboriginal health workers*
3. *delivery of comprehensive primary health care to Aboriginal communities through support for Aboriginal-controlled services*
4. *responsibilities of community leaders to promote health, and governments and services to provide programs, funding and staffing*
5. *improved standards of environmental health, including housing and essential services to a standard enjoyed by the broader Australian community*
6. *development of partnerships with sectors whose activities impact on health*
7. *a more strategic approach to research, including evaluation of interventions*
8. *implementation of integrated funding models allowing for collaborative*



- longer-term planning of programs and services*
9. *increased accountability to Aboriginal communities and governments for delivery of health services* (pp. xv-xvii).

Reports of diverse (South Australian and beyond) initiatives, programs and services designed to improve the health and wellbeing of Aboriginal Australians can be found in the literature [14-20]. Viewed in the broader context of Aboriginal disadvantage, they strike a positive note - and also a paradox, as pointed out by Lowitja O'Donoghue in a major address titled *Towards a culture of improving Indigenous health in Australia* [21].

O'Donoghue cited much of what has happened in the name of improving Aboriginal health as 'knee-jerk reactions to particular problems' (p.64):

*There is a tendency for politicians to intermittently visit outback communities, especially at election times, and then go back to Canberra and recommend another review, another feasibility study, another flow chart, or another one-off pilot program* (pp.68-69).

While advocating a big picture approach and 'real' head and power shifts, O'Donoghue also stressed the importance of not overlooking 'what is happening on the ground' and celebrating 'the small victories, the breakthroughs in particular communities' (p.68).

In a similar vein, in an address delivered in April 2002, Pat Anderson stated Aboriginal health was in a state of turbulence, providing opportunity for debate and new solutions [22]. She believed there were moves to reintroduce 'mainstreaming' - 'to close down services designed and run specifically by Aboriginal people, for Aboriginal people' - and that this would 'return us all to the 1950s'. The main thrust of Anderson's address was that health and education are linked intimately together, in that advances in health will not be achieved without education. As she stated, 'We need both well-educated Aboriginal people and the willing cooperation of non-Aboriginal professionals'. This, however, is only an interim solution according to Anderson, who believes that:

*Ultimately, the problems of ill health in Aboriginal communities will be faced and solved by the people of those communities* (p.13).

Anderson's last point was reinforced in an article that appeared in The Weekend Australian in March 2002 [23], citing Noel Pearson:

*I think Noel is right when he says that communities also have to take charge of themselves and not just think that the solution lies in telling people what they have done to us. As they make their way through reconciliation, so we've got to make our way through the healing of our communities ... nobody else can do that for us.*

The newspaper reported on interviews with Australia's 'new wave' of young Indigenous leaders - their frustrations, plans and visions for Indigenous Australia, channelled through organisations like the Australian Indigenous Leadership Centre. The biggest breakthrough was seen to be increased participation by Aboriginal Australians in university study with Aboriginal lawyers, doctors and economists graduating in growing numbers (about 8000 Indigenous people now study at university, compared to less than 100 people 30 years ago).

This is the complex backdrop against which the mental health (including the social and emotional wellbeing) of Aboriginal Australians is now considered.

## **Mental health of Aboriginal Australians**

### **Differing conceptions**

There is an 'asymmetry', as Ernest Hunter (a psychiatrist and often cited author in the field of Indigenous health) has termed it, between mainstream and Indigenous definitions of mental health [24]. From an Indigenous perspective, mental health embodies 'holistic constructions involving considerations of spiritual, social, cultural, physical, economic and political issues', whereas mainstream understandings 'focus on disorder' (p.5). This asymmetry is brought home by Sheldon's detailed account of the mind shift necessary to conduct a psychiatric assessment of remotely located Aboriginal Australians [25]. Indigenous mental health promotion is interwoven with both health promotion generally and social justice. 'It is thus both a set of activities and a political process' [24](p.8). As such, it is an elusive and complex concept. Nevertheless, in this paper [24] Hunter reported many specific initiatives and in doing so, cautioned against recoiling from or denying the enormity of the social changes needed, saying 'There is little to be gained by being trapped in the doldrums of idealism or fatalism' (p.10).

### **All-Australian context**

The multiple factors adversely affecting the general health of Aboriginal Australians - economic, social, cultural, environmental and political - also markedly detract from their mental health. While common sense has pointed to this fact for many decades, only in recent years has the mental health of Indigenous Australians received serious attention. Indeed, the mental health of the Australian population in general was not specifically and comprehensively addressed at a national level until the *National Mental Health Strategy* was developed from three key Commonwealth mental health policy documents in 1991-92 [26](p.78). These policy documents were generated after lobbying from concerned parties. Through an extensive

consultative process they emphasised active participation by individuals in decisions affecting their lives [26](p.79).

In 1993, the *Report of the National Inquiry into Human Rights of People with Mental Illness* (Burdekin Report) [27] resulted from data collected from numerous sources over several years and pointed out many abuses of consumers' rights.

*This Report has led to increasing public and government recognition of the historical legacy of discrimination and exclusion that have denied people with serious mental health problems access to quality care, including many health and welfare services [26](p.79).*

Subsequent to this report, the *National Standards for Mental Health Services* were developed in 1997 out of similarly extensive collaboration with stakeholders. The Standards emphasise end results for consumers and 'reflect a strong value base, related to human rights, dignity and empowerment' [26](p.80).

Further to these national developments, each State and Territory has developed mental health policies, all of which identify the importance of involving consumers in the 'planning, development, operation and evaluation of services', as well as 'service-providers, non-government organisations and community leaders' in consultation processes [26](p.86). A series of very recent policy statements developed by the Department of Human Services in South Australia (still in draft form) addresses better management of acute psychiatric services in the State [28]. Titled the *Mental health emergency demand management policy*, it is designed to meet an increased demand for emergency care by reshaping and improving existing services. While the policy does not specifically identify Aboriginal people, they are embraced within the general identification of patients, clients and consumers.

## **Aboriginal context**

It is largely, but not entirely within the above policy parameters that the mental health of Indigenous Australians has attracted growing attention over the last decade. Hunter reminded participants at the 3rd National Rural Health Conference in 1995 that because Aboriginal Australians are so disadvantaged as a group, it is 'no surprise' they are at greater risk of mental health problems [29]. He judged the record of providing basic clinical services to Indigenous Australians suffering psychiatric disorders as 'abysmal'. In 'full consciousness of a long history and continuing legacy of well-meant but ill-fated interventions', Hunter advised mental health professionals they were in no position to demand or impose - only to advise. The 'sting', according to Hunter, is that while social change is necessary, it is not the province of non-Indigenous professionals to direct it.

An influential and often cited report is Swan and Raphael's (1995) *Ways Forward, A National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health* [30]. It is said this report did much to:

*...recognise the socially constructed concept of Aboriginal and Torres Strait Islander mental health, with its priorities of wellness, holistic health and culturally informed approaches to healing* [31](p.84).

An example of this report's influence is its extensive reference in a comprehensive handbook for psychologists working with Aboriginal Australians [32]. An evaluation of the national action plan for emotional and social wellbeing has also been undertaken [33].

Of greatest recent impact is the *Bringing them Home Report* [34], which has 'finally' put Indigenous mental health 'on the national agenda'. Some effects of removing Indigenous children from their families (the stolen generations) are now recognised - 'loss and grief, reduced parenting skills, child and youth behavioural problems and youth suicide' [34]. It has been suggested Aboriginal people may have:

*...internalised the major premise of the official policies of the period: that Aboriginal parents could not provide adequately for their children' and this, combined with other injustices, has contributed to the high rates of social problems in Aboriginal communities* [31](p.86).

More specifically, intergenerational trauma caused by family separation may be associated with:

- *personality disorders;*
- *an increased incidence of harmful alcohol and drug use and dependency;*
- *mental illness, in particular depression;*
- *poor socialisation, including educational under-achievement;*
- *increased incidence of anti-social and offending behaviour;*
- *a break-down of traditional patterns of social cohesiveness and social control* [35](p.21).

## **Relevant findings**

The inquiry into separation of Aboriginal children from their families found most mental health services are inappropriate for Indigenous people's needs:

- *Indigenous people view mental health differently to non-Indigenous people;*
- *non-Indigenous doctors and nurses often lack understanding of Aboriginal or Islander culture;*
- *social and community well-being is often ignored;*
- *rural and remote communities don't get the same services as cities and towns; and*
- *too many Indigenous people end up in mental hospitals or prison* [36](p.25).

These findings are borne out in the recent Australian Bureau of Statistics (ABS) publication *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*, which reports [9] (pp.73-76):

- In 1997-99, there were twice as many deaths from mental disorders for Indigenous people as expected for all Australians (data only available from Queensland, South Australia, Western Australia and Northern Territory), with 78% of these deaths attributed to psychoactive substance use.
- In 1998-99, there were 'more' (accurate rates are difficult to determine) hospital separations for 'most types of mental and behavioural disorders' for Indigenous people than expected, based on all-Australian rates.
- Intentional injury may be an indicator of psychological illness. In 1998-99 (based on all-Australian rates) there were 6 times as many hospital separations as expected for assault among Indigenous males, and 19 times as many for Indigenous females.
- 'Suicides accounted for 2.6 times more deaths than expected for Indigenous males and twice as many deaths as expected for Indigenous females.' An international literature review showed suicide rates among Aboriginal youth in New South Wales for 1996-98 were among the highest recorded.
- Antisocial behaviour that brings Indigenous people into contact with the criminal justice system is often the result of undiagnosed mental distress. 'In the year 2000, Indigenous males aged 17 and over were imprisoned at the rate of 3,318 per 100,000 compared with 280 per 100,000 for all males'; the respective rates for Indigenous females were 251 compared to 19 for all females.
- The 1991 Royal Commission into Aboriginal Deaths in Custody found when young Indigenous men were incarcerated, they often experienced 'depressive symptoms and unresolved anger', and when released from prison 'were likely to turn to substance abuse and violence'.

## Initiatives

Reports of initiatives promoting mental health for Indigenous Australians, as well as prevention and early intervention, are prevalent in the literature. Initiatives include national action, comorbidity and data base projects [37-40]. South Australian initiatives include action and implementation plans [41, 42], State capacity building and service delivery programs [43, 44], regional strategic direction and General Practitioner (GP) partnership projects [45, 46], and practitioner principles and guidelines [25, 32, 47-49].

*The National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000* [37] identifies Aboriginal peoples and Torres Strait Islanders as a priority group (pp.42-43). It reiterates that the mental health of Aboriginal people can only be understood within a context of whole community wellbeing plus historical events related to colonisation. Past misdiagnosis, stigma and lack of cultural understanding by mainstream

services are identified as inhibiting these services' acknowledgement of Indigenous mental health problems. The Action Plan emphasises Indigenous ownership of programs, increased culturally appropriate initiatives, joint planning between Aboriginal and mainstream organisations, and increased training and employment of Indigenous Australians in health and education settings. The specified outcome indicators in relation to Aboriginal Australians are:

- reduced racism and discrimination;
- improved capacity for communities to be self-determining and resilient;
- reduced socioeconomic disadvantage, violence, incarceration, family separation, substance misuse, depression and anxiety for communities; and
- reduced suicide and self-harm for those who are incarcerated.

Within this mental health scenario, medication management is now considered.

## **Medication management for Aboriginal Australians with mental health disorders**

### **Alcohol and other drugs**

Literature on the specific topic of medication management for Aboriginal Australians with mental health disorders is extremely scant (see pilot project discussed below). However, it can be considered within more general parameters, particularly in relation to alcohol and other drugs. For example, in South Australia for the period 1999-2000, there were a total of 30 programs directed at alcohol and other drug misuse: seven directed at alcohol; nine directed at alcohol and other (unspecified) drugs; two directed at alcohol and volatile substances; three directed at alcohol and cannabis; one directed at alcohol and heroin; four directed at volatile substances; one directed at heroin and amphetamines; and three directed at tobacco [50](pp.28-29). Compared with other states, per capita expenditure on these programs was the highest at \$256.33 [50](p.34), however Indigenous control of funds was the lowest at 77.8% [50](p.39).

The 1999 *Review of the Commonwealth's Aboriginal and Torres Strait Islander Substance Misuse Program*[51] reports increasing evidence of Indigenous people taking up drug use at a younger age. Alcohol is of most community concern and is strongly associated with tobacco use. Although Indigenous people drink less alcohol than the overall general population, those that do tend to drink to harmful and hazardous levels, with alcohol-related deaths being 3 to 5 times those of the general population (p.22). Kava, an intoxicating non-alcoholic beverage prepared from the plant *Piper*

*methysticum*, is of recent and special concern in areas of the Northern Territory, with heavy use resulting in toxic effects and general ill health (p.27). Petrol sniffing and other inhalants are primarily of concern in Central Australian and Top End communities, where young males are most likely to sniff and, if the practice is prolonged, suffer brain damage and long-term disability (p.27). There is evidence that sniffing is also prevalent among older adolescents and females [50](p.7).

Illicit drug use is of growing concern, especially in Sydney where mortality rates from communicable diseases associated with injecting drug use (notably heroin) are 12 times higher than the general Australian population [51](p.26). It is estimated that 22% of Indigenous people smoke cannabis regularly, compared with 18% of non- Indigenous people [50](p.11). Illicit polydrug use is also apparent. A study in Western Australia of young Aboriginal people showed that by 1997, 48% of those aged 15 - 17 years old were frequent polydrug users [52]. It has been noted that little research has been conducted on illicit drug use by Aboriginal Australians [50](p.11).

At Commonwealth level, the Office for Aboriginal and Torres Strait Islander Health (OATSIH) funds 69 specific substance misuse services/projects (within the Department of Health and Aged Care). Twenty-two of these are residential rehabilitation services and the rest are primary health care and community programs [51](p.6). The review states that despite 'Indigenous specific substance misuse services' having been in operation for 20 years, 'little is known' of their long-term success rate (p.6), and despite the misuse of alcohol, drugs and other substances having been extensively researched, 'this has not led to improvements in health' (p.13). It goes on to outline a series of 'Priorities for Action' in the following areas:

- national policy framework and five year strategic plan;
- control of supply and diversionary activities;
- prevention and early intervention;
- specialist and treatment services;
- workforce issues;
- intersectoral and local linkages; and
- research and data collection.

Much suffering among Aboriginal people can be attributed to psychoactive substance misuse. The OATSIH Review emphasises that 'dispossession from language, culture and land goes hand in hand with substance misuse', and that these broad social, cultural and economic factors must be considered when developing responses [51](p.15). One such response produced by the Department of Health and Aged Care is a comprehensive document outlining national recommendations for the clinical management of alcohol-related problems in Indigenous primary care settings [53]. Management issues addressed relate to the spectrum of problems associated with intoxication,

dependence (including complicated alcohol withdrawal and delirium tremens, Wernicke's Encephalopathy and Korsakoff's Psychosis), medical comorbidity, psychiatric comorbidity and continuing care. Comorbidity issues have been specifically considered in recent reports [38, 40].

Apart from official reports, many papers address issues associated with harmful alcohol and other drugs, such as the use of tobacco, alcohol and other drugs by young Aboriginal people (increasing) [52], the association between smoking and mental disorders (strong) [54], and characteristics of needle exchange in Darwin (high risk) [55].

## **Other medications**

Licit medication, including over-the-counter and prescription drug use by Aboriginal people receives little attention in the literature. One pertinent study examined older Aboriginal women's experiences of medications in urban South Australia [56]. de Crespigny (the principal investigator of the research reported here) and her co-researchers reported on a cohort of Aboriginal participants within a larger study on the topic, comparing them with the non-Aboriginal participants. They found that despite the urban Aboriginal women having close connections with metropolitan Aboriginal services, general practitioners, pharmacists and family members, there were 'significant deficits in their knowledge and skills in managing their medications' (p.6). For example, there was evidence of medication being shared, dosages changed, and instructions being poorly understood and managed. As with the non-Aboriginal women, it was common for medications to only be recognised by shape and colour, and for a heavy reliance on memory for dosage and time of administration [56]. As one Aboriginal participant said, 'I usually take them if I don't forget' (p.11). The researchers found 'an urgent need for better education, training and support' for all health workers involved with older Aboriginal women.

Other papers make minor reference to medications. For example, it was revealed the reason a 30-year-old woman could not manage the spacing of her insulin injections for gestational diabetes was because she could not tell the time [57]. In a study of Aboriginal perspectives of diabetes in a remote Northern Territory community, 'only a few' participants thought their medications were of benefit in their treatment, with one respondent stating she only took the medicine because the doctor told her to [58]. In terms of prescribing rates, another study found 'at least one medicine was dispensed or prescribed' at 63.2% of consultations at an Aboriginal community controlled health service in Darwin, compared to 53.5% of consultations in Australian general practice [59]. Prescribing and dispensing issues in remote areas of the Northern Territory have also been explored [60]. In a study of communication between hospitals and isolated Aboriginal community health



clinics, confusion was found to exist between resident and district medical officers, and primary carers in relation to discharge medication - documentation, duration of medicines supplied and delivery times [61]. A recent study by pharmacists that examined quality use of medicines in 11 Aboriginal Health Services across Australia identified Aboriginal communities as having special delivery and dispensing problems. Recommendations arising from the study emphasised the need for coordinated medication services and availability of quality medication information for Aboriginal Australians [62]. Similarly, research in remote SA [64] explored and addressed issues impacting on quality use of medication including information and education for consumers and health professionals, cost and equity of access.

## **Pilot Project**

No literature could be found specifically addressing medication management for Aboriginal Australians with mental health disorders - except for the pilot project of the research reported here [63] (attachment 8). Given the close between mental health disorders, including psychoactive substance use disorders and the many social, economic problems experienced by Indigenous Australians, many (possibly most) of the Aboriginal people referred to in other contexts in this review are likely to suffer mental illness and to take medication. It is surprising and concerning therefore that the particular needs of these individuals apparently have not attracted attention. It also clearly points to the need for research on the topic.

The pilot project of the research reported here [63]. Given the close association between mental health disorders, including psychoactive substance use disorders and the many social, cultural and economic problems experienced by Indigenous Australians, many (possibly most) of the Aboriginal people referred to in other contexts in this review are likely to suffer mental illness and to take medication. It is surprising and concerning therefore that the particular needs of these individuals apparently have not attracted attention. It also clearly points to the need for research on the topic.

The pilot project [63] explored the experiences and views of Aboriginal people with mental health disorders, carers and health workers in relation to medication use. Findings centred around issues of: poverty; shame; understanding of mental illness and medications; coordination of services; adequate and appropriate services; the relationship between alcohol or other drugs and mental illness; and burden on carers (p.5). Recommendations are wide ranging, reflecting an earlier call for responses to drug problems to take into account the broad factors accounting for Aboriginal disadvantage [51]. Some specific recommended actions include: developing multiple

means by which Aboriginal people can increase their understanding of medications for mental illness, 'including purpose, safe use, compliance, interaction with other substances, side effects, storage and disposal'; developing integrated service delivery systems including distribution of medications and communication between health services 'so that over prescribing and conflicting advice is minimised'; assistance with budgeting for medications; and developing pathways for quality use of medications for Aboriginal people on discharge from hospital and release from prison [63](pp.48-49).

## Conclusion

This review has highlighted what might be considered a very weak patch in a richly worked quilt. Indeed, to take the analogy a little further, the entire field of Aboriginal health in Australia could be conceived as such a patchwork quilt: constructed by numerous individuals and groups with sometimes contesting visions of what is needed to make it an excellent quilt. Despite the best intentions of all involved, the quilt is still to provide maximum warmth:

*...to ensure that Aboriginal and Torres Strait Islander peoples enjoy a long and healthy life enriched by a strong living culture, dignity and justice [13].*

Emotion runs deep through the literature on Aboriginal health. It is difficult to remain dispassionate and perhaps it is better that we do not, for good research requires a passion of purpose and passion for making a difference. We acknowledge the tragic consequences for Indigenous Australians since colonisation and the complexity of the challenges all Australians face in ensuring the highest standards of health for all in the future. We also remain optimistic about helping to meet this challenge by researching a hitherto neglected topic.

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# Chapter Five

## Interviews

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### **This chapter was prepared by:**

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### **Introduction**

This chapter provides an overview of the qualitative findings from all interviews conducted with Aboriginal people with mental health problems, carers and family members, and health and social service workers from different regions in SA. To achieve this, each regional report was examined and a meta-analysis conducted. Firstly, common findings were identified across regional reports and studied in light of the research aims and objectives. They were then reconceptualised as major themes and brought together into one coherent summary. In providing this broad view, much of the richness of detail to be found in the individual reports is unavoidably lost. Importantly, substantiation of the major findings presented in this summary lie in the regional reports (attachments 1-7), where actual data in the form of participants' verbatim responses are recorded. Therefore readers are asked to peruse the reports of research done in individual regions, especially if wishing to identify specific findings from a particular area.

We believe the overall findings from interviews with clients, carers and workers reveal problems of a magnitude not previously realised - mental health problems and medication management among Aboriginal people are major issues requiring immediate and sustained attention if the health and welfare of the South Australian Indigenous population is to be taken seriously. We also wish to point out that positive stories and anecdotes can be found within the findings of individual reports. Considering the SA-wide scene as a whole, some participants cited occasions when they felt genuinely cared for within the health care system and when their health care needs were adequately met. These individuals appreciated the increasing efforts of individuals and government to provide dedicated Aboriginal health services. They felt listened to and respected (by both Aboriginal and mainstream services), understood their medication management and considered their medication improved their health status. In short, they experienced high quality, culturally sensitive care. This bodes well for developments in safe medication management for Aboriginal people, as the potential for positive change is present. However, tragically, the vastly greater proportion of

findings reflected a seriously neglected aspect of health care, in particular mental health care, with grave implications for individual and community wellbeing.

Before moving to the summary of interview findings, a brief description is provided of the participants, and how these qualitative data were collected and analysed. In terms of study design, these aspects were common to each regional project.

## Participants

The inclusion criteria for interview and focus group participants were:

- Aboriginal person with mental health problems such as anxiety, depression, psychosis, dementia, acquired brain injury or other mental illness, or social and emotional distress, including problems related to drug and alcohol use; resident in South Australia, not hospitalised and adult; or
- carer or family member of the above; or
- worker who provides health, social and other services to the above, such as Aboriginal health workers, social workers, registered nurses, doctors, pharmacists, educators and other key service providers..

Participants were a convenience sample of volunteers. Some were purposively invited to maximise representation of all the major stakeholders.

Altogether we conducted 58 interviews/focus groups, with a total of over 130 participants. Participants were drawn from urban, rural and remote regions of SA, including metropolitan Adelaide, Port Augusta, Port Lincoln, Coober Pedy, Riverland, Murray Bridge and Maitland.

## Data collection

The semi-structured, face-to-face interviews with Aboriginal people with mental health problems, carers and other family members were conducted by specifically trained Aboriginal research assistants, or other members of the research team who were acceptable to participants. Their purpose was to elicit direct and particular experiences, knowledge, concerns, contexts and issues associated with being, living with and/or caring for an Aboriginal person with a mental health problem, focusing on medication and other substance use. A member of the research team or an Aboriginal research assistant also conducted interviews/focus groups with a range of professionals who provided services to Aboriginal people. The purpose of these interviews/focus groups was to identify and discuss pathways used for



service provision and giving medication/health information, and to examine the usefulness of information, advice and support regarding medication use and related health issues. They also explored Aboriginal carers' and others' education and training needs relating to safe medication use by Aboriginal people with social and emotional wellbeing problems.

An interview guide was used that included a section for recording demographic data and sections for collecting open-ended qualitative data (the interview guide is appended to this chapter). Interviews were audio taped for later transcription, or handwritten notes were taken. All participants were fully informed about the research and gave informed consent (the information sheet and consent form are appended to this chapter).

## **Data analysis**

Data for each region was analysed separately. Each interview/focus group transcript was subjected to a preliminary thematic analysis, based on the headings in the interview guide. Key information and quotes from interviews were coded under those headings while reading and re-reading the transcripts and listening to the tapes. These were then categorised further into themes, based on the interview guide and other concepts that emerged from the interviews. Finally, all findings were integrated into one document to give an overall picture, highlighting common themes, key issues, similarities and differences [1]. The analysis process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and as deeper analysis occurred [2]. Other researchers from the team cross-validated the analysis. Preliminary findings were presented to steering committee members and key informants for further elaboration and validation. Notes from these meetings were included as data where appropriate. The steering committee in collaboration with the project team developed recommendations based on the interview findings. The researchers directly involved in the local project recorded their reflections and ideas emanating from interviews with key informants, focus groups and steering committee discussions, and these too were included as data. We have used this analysis approach to study design previously [3-6].

## **Summarising findings of interviews from all SA regions**

The findings of this project could not be narrowly conceived. While the research focus was specific - medication management among mentally ill Aboriginal people - the outcomes were far reaching in their context and implication. This is reflected within the regional reports where findings and subsequent discussions go far beyond the specific research topic to issues of

profound significance to Aboriginal people. In writing this chapter, we were in turn challenged to go beyond what might traditionally be expected of a summary: a brief account confined to the focus of concern, as indicated by questions in the interview schedule. This project clearly required a more highly contextualised approach.

The major themes presented below represent SA-wide findings from interviews and focus groups with Aboriginal people with mental health problems, carers and family members, and workers who provide them with health and other services. The findings are contextualised only as indicated by the data. While the questions posed to participants might have been quite specific, the responses ranged over issues of very wide concern. This produced a 'ripple' effect, whereby it was necessary to locate the specific medication management problems within ever widening parameters. Not to adopt this approach would have been an injustice to our participants who courageously shared elements of their life stories with us.

## **Major findings**

### **1. Social and emotional wellbeing issues deeply pervade the lives of all Aboriginal people and seriously diminish the value that individuals place upon medicines and the potential of these medicines to improve their quality of life.**

Mainstream definitions of mental illness proved of little value in this project. While we encountered some individuals who had been diagnosed with a condition such as schizophrenia or bipolar disorder, and were being treated accordingly, the broader definition of social and emotional wellbeing was much more useful. It was meaningful to participants, as it touched upon all aspects of their lives including not only social and emotional factors but also economic and physical factors - it was a whole of life approach. Significantly, many Aboriginal participants (clients, carers and workers) had chronic physical health problems like diabetes and cardiovascular disease.

Findings from all regions, whether at individual, family or whole community level, revealed social and emotional wellbeing issues - aspects of Aboriginal people's lives about which they were deeply unhappy, felt heavily burdened by, or knew were badly out of balance but had no control or power to change or bring back into balance. These issues related especially to:

- grief for family members who had died through suicide, overdose, violence, accident or ill health, and associated traditional grieving processes;
- anger at past and continuing injustices towards themselves as Indigenous

people by the white population of Australia, including incarceration issues;

- feeling overburdened and overwhelmed by constant carer responsibilities;
- chronic poverty, substandard living arrangements, inadequate transport, malnutrition and poor physical health leading to chronic feelings of hopelessness, inadequacy and powerlessness;
- confusion and unhappiness over stolen generation family members - being unable to find a family member or finding a member only to experience rejection;
- disputes and tensions between family and community members concerning marriage breakdowns, children's misbehaviour, unemployment, lack of money, inter community conflicts and rivalries, and issues to do with visiting relatives and relatives on parole or recently released from prison.

The deeply pervasive nature of these issues in people's lives meant that virtually no Aboriginal people were free of their effects. All Aboriginal participants in the project were suffering a degree of social and emotional stress. The impact of this on medication management was that generally everything associated with medications took a lower priority to the issue (or issues) at hand. A participant might have expressed a keen desire to take their medication as ordered in an interview situation but also acknowledged this was unlikely to occur due to one or other of the issues raised above. In many situations and instances, taking one's medication was simply not important, even when not to do so might be debilitating or even life threatening. Social and emotional wellbeing issues thus markedly and adversely affected medication compliance.

## **2. Aboriginal health services and providers are themselves subject to the same stressors as the wider Aboriginal community, plus additional bureaucratic stressors, which weaken their ability to provide effective medication services.**

The advent and increasing activity of health services dedicated to providing culturally appropriate care to Aboriginal people is a major advance in promoting Aboriginal health and wellbeing. They are services run for Aboriginal people by Aboriginal people. Ideally, they are the answer to many problems in Aboriginal health care. Our findings showed this was indeed just an ideal. Not only were those running the services experiencing social and emotional wellbeing issues themselves and subject to the same stressors as the clients they served, they were also burdened by the wider bureaucracy

in which they functioned. The complexity of funding avenues, staffing arrangements, lines of authority, range of services, changing government directives and priorities, poor communication channels between Aboriginal and mainstream services, and poorly integrated services at all levels posed major challenges for staff in all regions. Inadequate funds, lack of resources, constant staff shortages and high staff turnover exacerbated the situation. The need for more accessible and relevant training was highlighted in every region, in particular regarding medication management, mental health, drug and alcohol use, and cultural safety. It was agreed that building the capacity of both the Aboriginal and mainstream workforce to provide effective, evidence based care is essential.

From the medication management perspective, Aboriginal health workers, drivers and others played a very important and active role in delivering and administering medicines to Aboriginal clients, often located some distance from the health service, such as in outlying communities and camps on town fringes. However, this was only one of a very wide range of helping activities performed by these workers, who had limited time to devote to medications. This meant medications could not always be delivered at appropriate times or were left for the clients to take at later times when it could not be assured they were actually taken. Sometimes medications had to be left either with another person because the client could not be located, or in a potentially unsafe place. Furthermore, the role and responsibility of different workers in relation to medication was often ambiguous. Many workers acknowledged gaps in their knowledge and understanding of medications, and were concerned about putting their clients and themselves at risk. These difficulties were exacerbated by the personal stress workers were experiencing as members of their Aboriginal communities, and the stress of working in a bureaucratic maze. Medication management by Aboriginal health service providers was thus constrained by the personal issues, lack of training and bureaucratic challenges they faced.

### **3. Mainstream health services are not structured to meet the lifestyles and health problems of Aboriginal people, preventing the appropriate management of medicines at the time and place of greatest need.**

Some Aboriginal participants chose to use the local mainstream health service as their principal source of health care. In other instances, Aboriginal services were not available. Specialist service providers were almost always non-Indigenous. The mainstream services accessed were usually the local hospital or general practitioner clinic. Aboriginal people

wanted and needed to access these services 24 hours a day, sometimes more often at night, and often as a result of an unexpected event, such as injury resulting from violence, illness resulting from a medication mishap or overdose, or misuse of alcohol or other drugs. They needed to be able to present themselves to a health service and receive prompt and comprehensive service. Findings showed their needs contrasted sharply with the nature of mainstream services offered, which generally required an appointment made in advance or a serious medical emergency for immediate attention. The expectations and practices of Aboriginal clients and mainstream service providers were clearly in conflict. Further, the timeframes to which Aboriginal people adjusted their lives (such as 'sorry business' taking precedence over all else) and prioritising family responsibility over personal health problems, meant appointments, when they were made, were often not kept. Lack of transport for Aboriginal people was also reportedly a major concern in some regions, requiring long walks in adverse conditions that made time of arrival at the clinic uncertain and recall for regular appointments unrealistic. Whether or not clients chose to use an Aboriginal health service for their routine health care, many had to use mainstream metropolitan hospitals and mental health facilities at times of crisis or specialist need. There were many reports of lack of integration of mainstream, regional and local services, and poor communication between service providers and families/carers, which put clients at unnecessary risk.

From the medication management perspective, this mismatch between clients' needs and the health services offered often meant necessary medications were not available when needed, or when they finally became available, they were no longer the appropriate treatment. Participants reported much pain and suffering as a result of being unable to access health care when they believed they needed it. These instances usually involved a medication, often to relieve severe pain. Dissatisfaction with mainstream services also led to 'doctor shopping', with Aboriginal patients going from one doctor to another to seek attention, and sometimes securing more than one prescription or dose of medicine, often analgesics, which are reportedly a major source of addiction among Aboriginal patients.

Mismatches between traditional understandings of wellness and sickness, and Western medico-scientific understandings of health and disease exacerbated these tensions. Mainstream health services tended to follow the medical model, dealing with the various physical and mental illnesses and conditions in an uncoordinated fashion. The traditional worldview requires a holistic approach that incorporates individual, family and community bio-psycho-social issues, which means taking the time to listen. As a result of these mismatched worldviews and expectations, some Aboriginal people are sceptical about diagnoses and mistrustful of medical advice about treatments and lifestyle change.

**4. Aboriginal health services can unwittingly erode trust and confidentiality in their clients, which can result in Aboriginal people not using the services and missing out on culturally appropriate management of their medications.**

Because Aboriginal health workers and other Aboriginal service providers are members of the local communities they serve, they often know about, and might even be personally involved with the issues about which their clients seek assistance. This poses a great burden of responsibility upon the workers to engender trust and maintain confidentiality. It might also detract from their ability to maintain a helping role because they are so close to the issues themselves. Traditional rules about interactions between family members add a further complication in some communities. As a result of these complexities, some Aboriginal clients preferred to use a mainstream service (about which they experienced varying levels of satisfaction).

From the medication perspective, we found some Aboriginal people at risk of 'falling between the cracks' of Aboriginal and mainstream health services. It was possible they were not receiving the culturally sensitive care hoped for at the Aboriginal service, or the kind of attention they desired at the mainstream service. Given the multiple, major health problems experienced by Aboriginal people and the important role medication has in managing these problems, the potential for further deterioration of health was very real for these people. The impact of social and emotional wellbeing issues in the lives of Aboriginal people meant it did not take a great deal to deter them from seeking or taking their medicine. There was almost always something more important to attend to. Thus, without the active support of an Aboriginal health service, some Aboriginal people experienced inadequate medication management.

**5. Many Aboriginal people lack English language literacy and numeracy skills, which seriously detracts from their understanding of their medications, including instructions for administration, purpose, actions and side effects.**

Taking medication safely and effectively ideally requires acceptance of the health problem as one that can be controlled by medication, and knowledge

and understanding of the drug itself and how it works, and why and how it should be taken as ordered. This represents a sophisticated grasp of the English language (in most Australian mainstream health services). Aboriginal people whose first language is not English and whose formal education may have been limited or minimal are thus severely disadvantaged.

Our findings showed Aboriginal people in the main did not understand their medical diagnosis, the action or side effects of their medicines, the significance of the timing of administration of their medicines, or the consequences of not taking their medicines. Many were unable to correctly interpret administration and storage instructions on medicine labels or to identify when a repeat medication was required. Some were unable to tell clock time and so could not follow instructions as to when to take a medicine. Some Aboriginal clients reported being unable to understand their doctors' explanations and instructions, and were unable to satisfactorily request further information. Many were on multiple tablets dispensed in dosette boxes that required literacy and numeracy skills, as well as motor skills, to use safely. We were very concerned our participants could not maintain safe and effective medication management (to the point of their lives being endangered) because they were not adequately proficient in English. Further, health workers reported they themselves were inadequately prepared to help clients understand their medications.

## **6. Inadequate living arrangements and remote living locations for many Aboriginal people mean the safe delivery, administration and storage of medications is jeopardised.**

Housing, including sanitation, running hot and cold water, household effects, refrigeration, and blankets and bedding were widely reported as inadequate, and rendered more inadequate by frequent additional family members visiting or staying a while. Further pressure was put on households because there was frequently at least one family member who was sick and required care from other members. It was not unusual for Aboriginal workers to go home from their carer responsibilities at work straight into carer responsibilities at home. Supplying an adequate quantity of healthy food in the home was a major concern for many Aboriginal people. Takeaway food was an attractive option for some until money ran out, and carrying food long distances to prepare in the home, was not feasible for some people. Living arrangements where too many people were crowded into too small a space with too few amenities, and where some family members were sick and unable to care for themselves, added to the risk of further health problems.

From a medication perspective, these living arrangements made the safe delivery, administration and storage of medications very difficult. Many homes were quite remote from the health services, making delivery dates and times uncertain. Sometimes health workers could not find the client when they arrived, or were advised by others they had departed for an unknown period. Sometimes there was no refrigeration to store medicines requiring low temperatures, or no safe cupboard to leave medications in. Sometimes other workers or volunteers delivered medicines with no knowledge of their administration or management. On other occasions, when the person for whom the medication was intended was not present, other family members took it instead, hoping it might help their problems. Overall, inadequate living arrangements impacted negatively on all aspects of safe and effective medication management for Aboriginal people.

**7. The ill effects of widespread alcohol misuse within Aboriginal communities result in medicines being inappropriately combined with alcohol, and misused or neglected, to the detriment of the individual's health and those in proximity.**

Health service providers across the board in all regions highlighted the problem use of alcohol as a major problem with destructive and tragic social consequences. Individuals' lives were reported as shattered, marriages broken up, children ill-treated and communities divided over the consequences of binge drinking accompanied by antisocial and usually violent behaviour. Despite numerous government and non-government interventions designed to address problem use of alcohol, the practice persists among some Aboriginal people. 'Dry zones' were reported as compounding the issue and driving drinking into homes where women and children were at even greater risk of physical harm. Some found they were unable to resist peer pressure to drink alcohol, as they were ostracised if they did not join in. Others found drinking the only escape from their profoundly meaningless and unfulfilled life circumstances. Some did not appreciate that once available money was spent on alcohol, there was no means to buy food to sustain other family members.

In terms of medication management, Aboriginal people who misused alcohol usually did not benefit fully from their medications because they were not taken, the effects were not fully felt due to mal-absorption or non-absorption, or sometimes adverse reactions were experienced due to the combination of medication and alcohol. Alcohol use problems were often



combined with mental illness and these individuals sometimes suffered major consequences (such as hallucinations or seizures) when they failed to take their medication as prescribed. Perverse behaviour was another feature that accompanied misuse of alcohol, such as overdosing or trafficking of medicines. All aspects of medication management were thus found to be more difficult with those who misused alcohol.

**8. Institutionalised and individual racism (covert and overt) is a widespread phenomenon in the community at large, which seriously diminishes feelings of self-respect and self-worth among Aboriginal people, which in turn diminishes their interest in personal health, including all aspects of their medications.**

Many Aboriginal participants reported being spoken to in derogatory terms, looked down upon, refused health services, left waiting longer, ignored and generally made to feel of less importance than non-Aboriginal people. While it was difficult for participants to show the cause and effect relationship between racism and their diminished self-worth - racism is too insidious to allow that - it was clearly apparent to us as researchers and professional health workers that they were profoundly affected by racist attitudes and practices. Informed by our knowledge of the history of Aboriginal colonisation and subsequent oppression of Aboriginal people in Australia, the faltering stories of many of our participants, combined with their generally hesitant (or alternatively at times, angry) presentation, all pointed to low self-esteem and feelings of worthlessness.

We were shocked and deeply disappointed to find these racist elements across all regions, whether at an institutional level (for example, a hospital practice of refusing to admit patients under the influence of alcohol), individual level (being ignored by a service provider), overt (in the face) or covert (behind the back). Indeed, it appeared some practices might have become so customary in the community at large that non-Aboriginal members would vigorously deny holding racist attitudes. Our participants' reports and personal observations convinced us otherwise.

From a medication management viewpoint, the effects of racism were deeply troubling. We believe they lie at the heart of many medication problems for Aboriginal people. Often lacking assertion, self-worth and hope, many Aboriginal people also lacked conviction and positive attitudes towards their health and medications. Although they wanted to be rid of their health problems, they did not fully understand how their medicines worked or why

it was important to keep taking them. They were easily deterred from taking them as instructed, took only those they perceived as helping them, or swapped them with other individuals' medicines that seemed to be better. If nothing seems worth striving for in life, or the future has no meaning, one's medicines are certainly not a priority.

## Conclusion

The major findings of this project indicate there is vast potential for improvement of medication management for Aboriginal people, all of whom suffer social and emotional wellbeing problems of some kind at any point in time. Indeed, we believe acknowledging the significance of this point - that all Aboriginal people suffer emotional wellbeing problems of some kind at any point in time - is a key to improving the many unsatisfactory findings about medication management described above. Each medication issue must be considered in the context of its associated issues and historical circumstances.

By sharing their stories with us, our participants demonstrated their desire for a better future. Some clearly articulated a wish for Aboriginal people to become more self-reliant and assertive. As one Aboriginal health worker stated:

*What's most important is being responsible for your own life really, ultimately.*

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## Interview guides

Semi-structured interview guides were developed for this project. The questions served as prompts for the interviewer who asked questions in his own words in a conversational style. Below is the guide for interviews with carers. Guides for interviewing people with a mental health disorder, and for the focus group with health workers were very similar.

### Demographics

Age        client ..... carer .....

Gender    client ..... carer .....

Role       client ..... carer .....

Community

Postcode

Language group

Type of accommodation

UBD reference

How long have you/client lived at your current address?

How many changes of address have you had in the past year, 5 years, 10 years?

In the past week, the number of people living in the same house as you was?..... Number Adults?.....Number of children?.....

Ages and roles of these family members.

Education level, (client who is focus of interview)

Education level, carer. (illicit medical/para-medical knowledge/training)

Length of time as carer.

Does being a carer prevent you from obtaining employment?

Is the client a pensioner (Y): ..... (N)

Any other type of benefits received?

Are you currently caring for clients other than .....? (how many, ages, regular/intermittent)

### Health Services

What are the health care services that you can use in your area?

(Medical, gender specific, chemists, community, respite, home help, home nursing, referral and access to specialist services, Aboriginal services)

How do you know about your local health services?

How often do you use these services?

How do these services help you?

How are you able to access these services? (include home visits)

Are these services convenient for you?

What if any difficulties have you experienced with these services?

How useful are these services?

Are there drug and alcohol services near you that you could obtain information from if you needed to?

What, if any, other health services would be useful for you?

## Current Health

How is .....’s general health at the moment? (is this better/worse re usual)  
What health problems has ..... had? (time and place/ surgery?)  
When did you first realise that ..... had a problem effecting their mental wellbeing? (advised by whom? when?.....)  
What term have .....’s doctor(s) called this illness?  
What do you understand about this illness?  
What helps .....cope with their illness? (what makes it better?)  
What aggravates .....’s illness? (what makes it worse?)  
What impact if any does .....’s illness have on your family?  
Has..... ever come to the attention of the police as a result of their mental health condition and if so, what happened?  
Who provides you information about .....’s health problem(s)?  
Has this information assisted you in having a better understanding about .....’s illness?  
Do you feel you still need more information ?  
What else would assist you in understanding/managing .....’s health problems?.  
Does illness/health problems affect other family members in your house?  
What do you understand about their health problems?  
What are the difficulties with caring for people in your family who are ill?

## Medicines

*( where appropriate, questions regarding non prescription medicines including S1, S2, and S3 will be interposed)*

Is ..... taking prescribed medicines at the moment? (explain what constitutes medicine)  
If .....’s taking prescribed medicines, why?  
How does ..... feel about taking medicines?  
What understanding does ..... have about his/her prescribed medication?  
What are the names of these medications?  
What strength are these medications and in what form are dispensed?  
What if any non-prescribed medication is ..... taking? (include alternative medicines, vitamins etc.)  
Why is .....taking these medications?  
How often does he/she take them?  
Does ..... doctor know about these other medications?  
Have you talked to .....’s doctor about .....’s prescribed medicines? Y...N...  
When?  
Did you understand completely what was said?  
If not, what was it that you didn’t understand.

Do you feel you can talk to .....’s doctor about his/her illness and medications?

What information did the doctor give you as to when and how the medication must be taken?

Was the topic of side effects discussed?

Was that information correct?

What side effects does .....experience as a result of taking prescribed medication?

Does .....regularly consult the same doctor/practice for their illness/medication management? (develop this where appropriate to include, dr. shopping, contraindication risk.....)

Is it your opinion that regardless of the doctor .....is seeing, that doctor has all the current medical information about .....?

If not, what are the problems you have encountered?

How else do you get information about .....’s prescribed medicines?

(eg; chemist, reading brochures, other health providers)

Is this information useful for you?

What other information would you like about the use of medicines?

How easily can you get .....’s medicines? (Prescribed and over the counter)

What if any barriers are there to you getting .....’s prescribed medicines when you need them?

How can/do you make sure that .....’s medicines are taken as and when they are meant to be taken? (checks & balances. Food qid etc)

How are you able to prevent another family member giving

.....medication? (eg: you give medn, and go out for a while. Whilst out ..... forgets they have had their medn. And asks another family member for it)

How do you manage when .....has:

Forgotten they have taken their medication and is asking you for it again?

Refused to take their medication? (expand on reason for refusal, confirm/eliminate shame component )

What happened? (probe physiological component)

Demanded to take control of their medication for ? reason(s)?

Has ..... deliberately/accidentally taken more medication than he/she should have? (circumstances, how many occasions?)

What happened?

Have you ever given or thought of giving extra medication rather than seeking help from a hospital/doctor when .....’s illness worsens?

Has ..... recently run out of prescribed medications? Y/N (for how long)?

Is it your responsibility to purchase .....’s medication?

Where do you get .....’s prescribed medication?

Do you, always ( ) usually ( ) sometimes ( ) rarely ( ) have medications dispensed at the same chemist?

Does the chemist consult with you about .....’s medication?  
always ( ) usually ( ) sometimes ( ) rarely ( )

Do you feel you can talk to the chemist about issues relating to .....’s medication management? yes ( ) no ( )

Can you tell me why you’ve said yes or no?

Have you experienced delays in getting .....’s prescribed medication?

(important question for rural/remote communities – frequency and length of delay)

Do you ‘put off’ getting .....’s prescribed medication? Why? (socio/economic)

Does .....drink alcohol or use other drugs (illicit) whilst taking their prescribed medication?

Including alcohol, can you tell me what these drugs are?

If alcohol or other drugs are used whilst taking medications, does this affect .....’s behaviour? (elaborate)

How does.....feel about using drugs such as alcohol, yarrdi, tobacco, speed and or heroin whilst taking medications? (expand where an answer is +ve)

What prescribed medications if any do other family member(s) take at the moment? (elaborate)

Where and how are they stored?

Are you aware of people sharing medicines? (why, circumstances, how often.....?)

What do you understand about people sharing their medicines?

How do you minimise this risk?

How is .....’s medication stored? (in relation to other medications in the house, can children access them?, are lids put back on and secured?...)

Has another family member(s) mistakenly taken medication prescribed for .....?

What happened?

Do you have medications in your house which, are no longer required?

Why do you keep them?

When the dosage of medicines is changed, how do you check the right dosage is being taken?

Do you keep prescription repeats at home or leave them at the chemist?

If at home, are they secure and easily located should you need to have them dispensed?

How do you measure liquid medicines?

Can you estimate and pour 10 mls of water in this glass? (pour the water into a measure)

The amount was.....ml.

Are you aware of or have you seen dosettes (show dosette) before?

Have you used or considered using one? (if yes, are you using one now, why did you stop etc/)

Do you think a dosette would be of assistance in the management of medications?

Do you know how to tell whether medication has expired or is damaged?

Is there anything in relation to your involvement with issuing medications that you want to add?

# Information sheet



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ABORIGINAL  
DRUG AND ALCOHOL  
COUNCIL (SA) INC.

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## Information sheet

*Better medication management by Aboriginal people with mental health disorders such as dementia and alcohol related brain injury, their carers and other family members.*

We are conducting research to learn more about these issues

Our research team is made up of members of the School of Nursing & Midwifery, Flinders University and the Aboriginal Drug and Alcohol Council, Inc. (SA), and Aboriginal Research Assistants from the communities.

Throughout the project we are working closely with key Aboriginal groups, service providers and people with mental health problems, including carers and other family members in SA, locally and state wide. Through consultation, interviews and focus group discussions, and written materials, we hope to learn about the actual needs and experiences of Aboriginal people who have mental illness, as well as those of their carers/family members. We are especially interested in learning about their medication use issues and related problems.

Once we have collected and analysed the information, and in full consultation with the Aboriginal communities and other concerned groups, we will formulate the findings and key recommendations in the form of reports. These will be disseminated to the Aboriginal communities, funding bodies, people and groups who are concerned with medication use and the emotional and social well being of Aboriginal people experiencing mental health problems.

If you would like to be involved or want any further information about this project please contact Helen Murray on telephone 08 8201 5587 or you are also welcome to email either of us.  
On behalf of the research team partners.

Yours sincerely

Dr Charlotte de Crespigny  
Professor of Nursing (Alcohol & Other Drugs)  
School of Nursing & Midwifery

Mr Scott Wilson  
State Director  
Aboriginal Drug & Alcohol Council (SA) Inc

Investigators Rotary and QUMEP

# Consent form



FLINDERS UNIVERSITY  
ADELAIDE • AUSTRALIA



ABORIGINAL  
DRUG AND ALCOHOL  
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## CONSENT FORM FOR INTERVIEW or FOCUS GROUP

I.....

being over the age of 18 years hereby consent to participate as requested in an audio-taped interview (or focus group) for the research project:

*Better medication management by Aboriginal people with mental health disorders such as dementia and alcohol related brain injury, their carers and other family members.*

1. I have read (or been told about) all the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on audio-tape.
4. **I am aware that I should keep a copy of the Information Sheet and Consent Form for future reference.**
5. **I understand that:**
  - I may not directly benefit from taking part in this research.
  - I am free to withdraw from the group or project at any time
  - I am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and any of my individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, there will be no effect on me regarding related service that is being, or will need to be, provided to me.
  - Whether I participate or not, or withdraw after participating, there will be no effect on my employment, personal or community involvement related to issues within this project
  - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the interview or focus group without disadvantage.
  - As the participant I may choose to verbally consent on tape prior to the interview or focus group.
6. I agree that the tape will not be made available to other researchers or people.
7. I have had the opportunity to discuss taking part in this research with a colleague, family member or friend.

### Participant's

**signature.....Date.....**

*I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.*

### Researcher's

**signature.....Date.....**



# Chapter 6

## Survey of Service Providers

---

**This chapter was prepared by:**

- Inge Kowanko
- Charlotte de Crespigny
- Helen Murray
- Mette Groenkjaer

**Also involved were:**

- Anita De Bellis, Mike Turner and Sharon Cruse from Flinders University
- Scott Wilson, Warren Parfoot and Geoffrey Hawkins from the Aboriginal Drug and Alcohol Council Inc. (SA)

### Acknowledgments

The project team thanks all survey participants for providing information.

The material in this chapter has also been published as a separate report:

Kowanko, Inge

Better medication management for Aboriginal people with mental health disorders and their carers - Survey of Service Providers

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### Introduction

Past and ongoing policies and practices have resulted in profound and prolonged grief, disempowerment and social disadvantage for Aboriginal Australians, leading to multiple physical, spiritual and mental health challenges that are perpetuated down the generations. The latest statistics indicate that the Aboriginal population is still much sicker, younger and poorer than the non-Indigenous population [1, 2]. Mental health disorders (problems of social and emotional wellbeing) are widespread among Aboriginal people [1, 3-5], and often complicated by other chronic illness and/or substance misuse [6]. Quality medication management can be difficult for many Aboriginal clients, their carers or other family members [7-14]. Evidence suggests that unsafe or inappropriate use of medicines is common, with potentially damaging physical, social and economic consequences [7, 15-17].

This paper reports on a purposive survey of a wide range of health and other human service providers across South Australia (SA) regarding their knowledge, understanding and role in medication management for Aboriginal people with mental health disorders. The survey was one component of a large three year SA-wide project 'Better medication management for Aboriginal people with mental health disorders, their carers and other family members'. The SA-wide project explored complex issues around medication use among Aboriginal people with mental health disorders including drug and alcohol problems, from urban, rural and remote SA communities. A multiple methods approach was used, integrating findings from interviews with clients, carers and health professionals; a survey of health professionals (reported in this paper); and review of key statistical data and documents. Based on the integrated findings, recommendations for improving medication management and related strategies to improve social and emotional well being of Aboriginal people were developed, implemented and evaluated. The project was conducted by a partnership of researchers from the School of Nursing & Midwifery at Flinders University and the Aboriginal Drug and Alcohol Council (SA) Inc, working closely with Aboriginal communities, Aboriginal and mainstream service providers, and other stakeholders. The project was funded by the Commonwealth Department of Health and Ageing Quality Use of Medicines Evaluation Program, and was conducted in 2000-2003. A report on the pilot study for this research has already been published [8], and other reports arising from the wider project are in preparation and will be published in 2003.

## **Aim**

The aim of the survey was to explore and describe the knowledge, understanding and role in medication management of a wide range of health professionals and related workers across SA who work with Aboriginal people with mental health disorders.

## **Method**

### **Developing the survey questions**

Survey questions were developed by the research team, guided by the steering committee, and informed by the literature and other data collected in the wider project. They comprised a mixture of open-ended and closed-ended questions. The survey was refined through an iterative process of drafting, testing and refining, and finally pilot-tested with 5 health professionals. Only minor adjustments were needed following the pilot. The survey form is attached. The first page is a cover letter, outlining the purpose of the survey, explaining that participation is voluntary and assuring anonymity and confidentiality. Ethics approval was given for the

survey as a component of the wider project by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggoorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of SA.

## **Administering the survey**

A purposive sample of workers and managers from health and human service organisations was selected from across metropolitan, rural and remote SA. The inclusion criteria were that they have some contact and involvement with Aboriginal people with mental health problems, including problems with drug and alcohol use, and the management of their medications. Key people in each organisation were contacted by telephone, inviting them to participate. Survey forms were sent by mail to those who expressed interest. They were given the option of filling in the form at their convenience and returning it by post, or of responding orally to the survey questions by telephone at a mutually convenient date and time. Each survey was given a unique identifier number for administrative purposes, linked to a separate and confidential listing of addresses, enabling reminder calls to maximise response rate. Data was collected in 2002.

## **Analysis**

The SPSS program was used for quantitative data analysis, using simple descriptive statistics and Pearson chi square exact 2 sided test to explore associations between certain variables. Qualitative data was analysed thematically. Results were integrated into a narrative report, illustrated with direct quotes from the responses to open-ended questions.

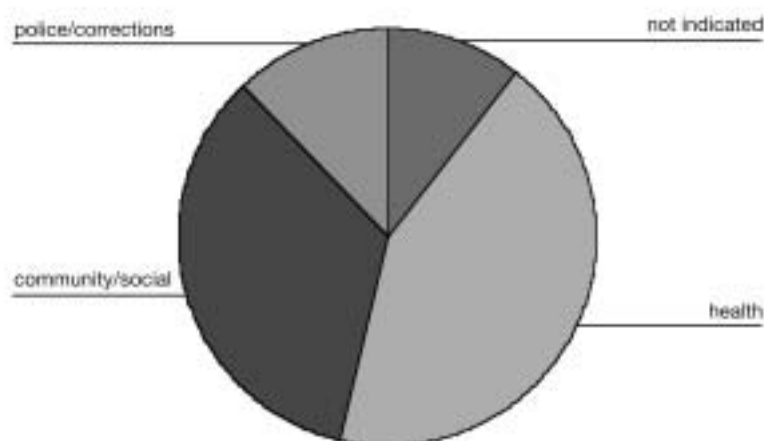
## **Results**

114 surveys were returned/completed out of 225 distributed (51% response rate).

### **General questions**

Respondents included a wide range of health and other human service workers including Aboriginal health workers, nurses, mental health workers, substance misuse workers, managers, liaison officers, social workers, police, pharmacists, GPs, community workers, counsellors, paramedics, educators, family support workers and others. For ease of analysis, the position/job titles were categorised broadly into health, community/social (includes education), police/corrections, and not indicated. Most respondents were employed in the health (43%) or the community/social services (34%) sectors (Figure 1).

Figure 1. Employment profile



They worked in organisations such as Aboriginal health services, community centres, medical clinics, police, drug and alcohol services, metropolitan and country hospitals, flying doctor, divisions of general practice, regional mental health services, correctional services, family and youth services, TAFE and non-government organisations.

The sample included workers from a range of rural, remote and metropolitan regions across SA (Table 1), and reflected the regions in which other aspects of this SA-wide project were conducted.

**Table 1. Number of responses from each SA region**

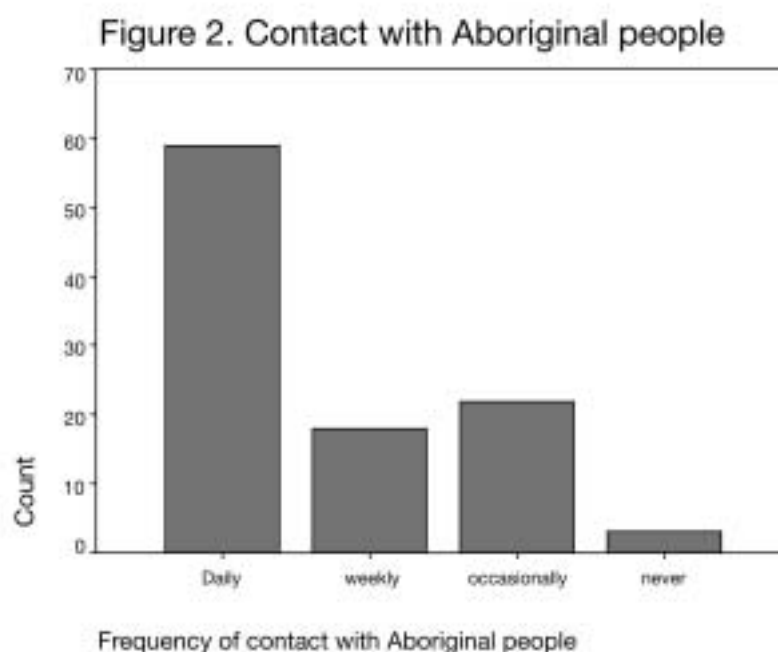
Region	Frequency
Not indicated	12
Port Lincoln and Ceduna	17
Port Augusta (including Copley, Nepabunna)	13
Riverland	10
Cooper Pedy	10
Murray Bridge	3
Metropolitan Adelaide	49
Total	114

17% of respondents worked in an Aboriginal community controlled organisation. 30% of respondents were of Aboriginal or Torres Strait Islander descent. Although these proportions may not reflect the composition of all SA health/community organisations, they are appropriate for this survey, as staff/organisations that deal with Aboriginal people were purposively selected. Not surprisingly, there was a positive association between working in an Aboriginal community controlled organisation and being of Aboriginal or Torres Strait Islander descent ( $\chi^2=5.44$ ,  $df=1$ ,  $P=0.038$ ). 84% of all respondents said their organisation employed people of Aboriginal or Torres Strait Islander descent.

69% of respondents had received some training about Aboriginal cultural awareness/safety, through workshops and in-service training in their workplace, as part of tertiary education, and informally through experience living and working with Aboriginal people. About two thirds of the respondents from the health and community/social sectors, and 100% from the police/corrections sector, reported receiving some cultural awareness education. Interestingly, respondents were less likely to have received such training if they worked in an Aboriginal community controlled organisation ( $\chi^2=7.79$ ,  $df=1$ ,  $P=0.009$ ), but this was not related to being of Aboriginal descent.

Participants were asked how many years experience they had in their current and related roles. There were 100 and 59 responses, respectively. The duration of experience in the current role varied widely, ranging from 0.1-30 years with a mean of 6.5 years. Around half the respondents had less than 5 years experience in their current role, perhaps reflecting high turnover of staff in these positions. The mean length of experience in related roles was greater at 13.6 years, with a wide range of 1-42 years. About two thirds of respondents had worked for more than 10 years in related roles, indicating a high degree of relevant experience. There was no significant difference between Aboriginal and non-Aboriginal workers in terms of years of experience.

Most people had frequent (daily or weekly) contact with Aboriginal people in their work, with over half having daily contact (Figure 2).

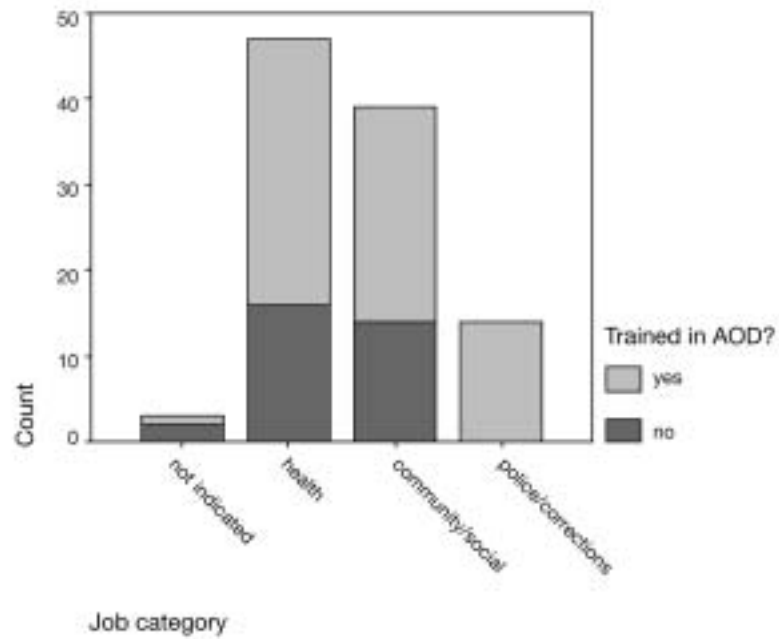


Not surprisingly, participants had more contact with Aboriginal clients if they worked in Aboriginal community controlled organisations ( $\chi^2=15.1$ ,  $df=3$ ,  $P=0.005$ ), or organisations that employ Aboriginal people ( $\chi^2=29.5$ ,  $df=3$ ,  $P<0.001$ ); if they had been trained in cultural awareness ( $\chi^2=8.7$ ,  $df=3$ ,  $P=0.03$ ), or if they were of Aboriginal descent ( $\chi^2=32.4$ ,  $df=3$ ,  $P<0.001$ ).

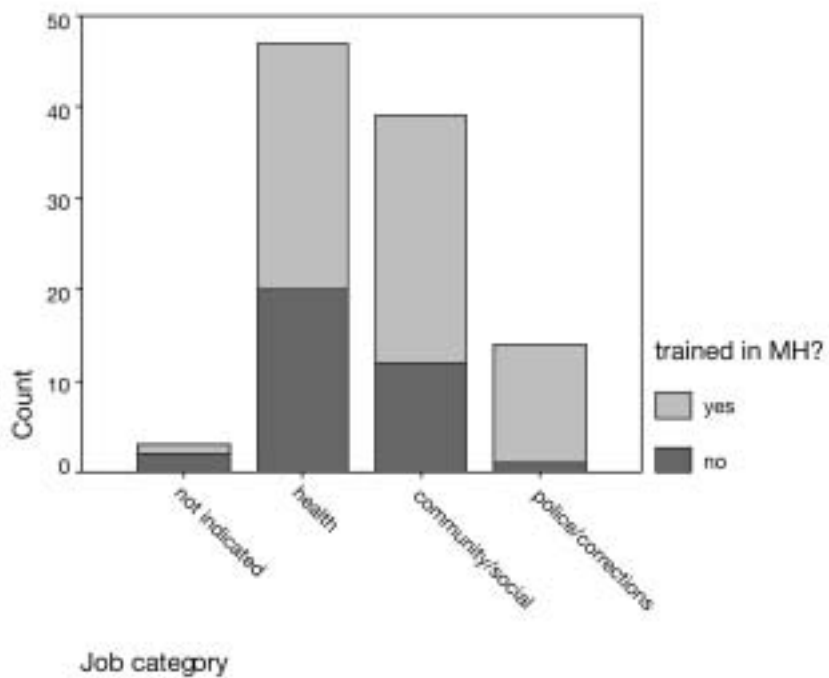
Most participants had professional and/or vocational qualifications, ranging from vocational education certificates in primary health care to postgraduate awards. Only 11 people (9%) had not been involved in any formal education beyond school.

The results show that one third of all respondents had received no training whatsoever in mental health (social and emotional wellbeing), and a similar proportion had never been trained in alcohol and other drugs. This deficit is of grave concern, given that the participants were selected from organisations that provide services to people with mental health problems, including substance misuse. Closer examination of the data showed that police/corrections workers had nearly all received some training, but that many workers from the health and community/social sectors were untrained in mental health and drug and alcohol (Figures 3 and 4). There were

**Figure 3. Number trained in alcohol and other drugs by job category**



**Figure 4. Number trained in mental health by job category**



statistically significant relationships between job category and being trained in mental health ( $\chi^2=7.6$ ,  $df=3$ ,  $P=0.05$ ), and between job category and being trained in alcohol and other drugs ( $\chi^2=8.7$ ,  $df=3$ ,  $P=0.03$ ). Those who had been trained in these fields had received it in several formats including special workshops and in-service education sessions, professional development modules, and specific tertiary courses or subjects. Several had attended short courses provided by this research team in direct response to our previous research findings in this three year, SA-wide project.

## **Understanding of medications**

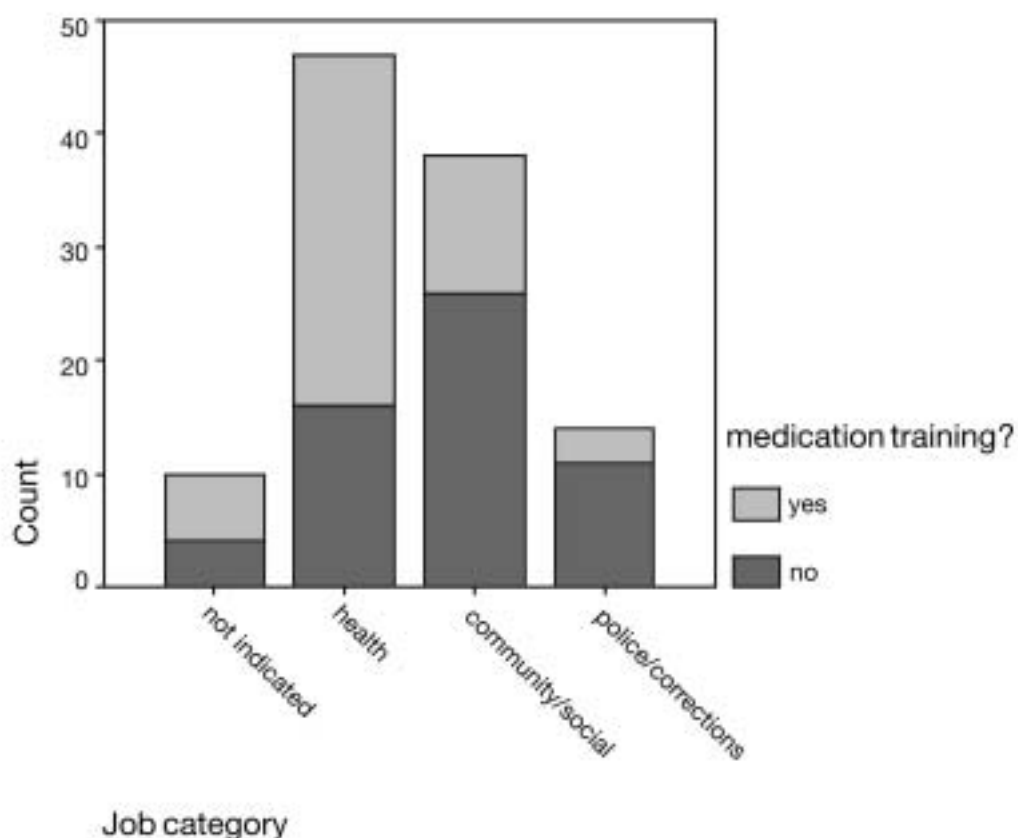
Most people (81% and 91%, respectively) rated their own understanding of prescribed and non-prescribed medicines, and their understanding of other drugs like illicit substances, alcohol and tobacco, as adequate/good. Interestingly, there was no significant association between these self-rated understandings and prior exposure to training in alcohol and other drugs or training in safe medication use, that is some people rated their knowledge highly but had not been trained. The reasons for this discrepancy are not clear, but may be related to the quality, relevance or recency of formal training, or respondents might over-estimate their understanding.

70% reported having a poor understanding of traditional Aboriginal medicines.

Only about half of all the respondents said they had received some training in quality use of medicines, eg as part of their professional or tertiary studies and as in-service workshops. Several had done the training offered through Pika Wiya and the Port Augusta pharmacists for Aboriginal health workers. It is of concern that most of the police/corrections workers, more than half of the workers in the community/social sector and 42% of health professionals are untrained in safe use of medicines (Figure 5). Inspection of the data revealed that all the registered nurses and pharmacists had been trained in medications, but that 2 of 6 doctors and many allied health workers said they had never received such training.



**Figure 5. Number trained in safe use of medicines by job category**



To put this result in context, about one third of all respondents reported ever giving or managing clients' medications, but a considerable number of these had never been trained for this role. Of the 36 people who reported ever giving clients medication, 11 had never been trained in safe use of medicines. Similarly, 7 of the 35 people who reported ever managing clients' medication were untrained. These people worked mostly in the health and police/corrections sectors.

Most people who had not been trained in safe use of medications believed it would be relevant to their practice, but had not yet taken part, citing factors such as access (40%), availability (48%), cost (36%), suitability (34%) and time (44%). Involving untrained workers in any aspect of medication management potentially puts the client and the worker at risk, and this was recognised by participants. For example:

*'We distribute drugs in our community, and clients ask us what these are for, but we only know what the doctor or RN tells us. We are reluctant to distribute drugs because some clients share these drugs and mix with alcohol. We should be educated more about medications and information*

*on what these medications are for.’ (#502, Aboriginal men’s health worker, remote area)*

Those who believed that training in safe use of medications would not be very relevant mostly gave the reason that handling medications was not part of their job. However, these people often wanted basic information to inform their work with Aboriginal people with mental health problems and to give to community members, eg:

*‘Whilst we might play a critical role in first contact intervention, as police we have no role in treatment. We act in a referral role when treatment is required. Sometimes treatment intervention is not appropriate but a good leaflet/pamphlet which we could provide to persons/supports might assist in the sourcing of assistance prior to police intervention being required.’ (#542, community program manager, police)*

## **Health service issues impacting on Aboriginal people with mental health problems**

Participants were asked to nominate major health service issues in urban, rural and remote areas that impact on Aboriginal people who have mental health problems, based on their experience. 102 people completed this question, and the results are collated in Table 2. In urban areas, the most frequently nominated service issues were money problems and racial discrimination, with availability of traditional health care and specialist mental health services also named. Money problems and transport were the most frequently nominated service issues for rural and remote areas, where availability of a range of special services, access, reticence to use services and racism were also seen as important service factors.

**Table 2. Health service issues impacting on Aboriginal people with mental health problems**

Health service issue	Percentage of respondents nominating each issue		
	Urban	Rural	Remote
Health service availability	20	49	47
Access to health services	26	47	46
Reluctance to use health services	39	47	37
Transport to/from health services	37	57	50
Availability of specific services for Aboriginal people	35	46	39
Availability of gender specific services	27	43	37
Availability of specific services for youth	32	50	45
Availability of specific services for older people	24	42	39
Availability of specialist mental health services	40	54	51
Availability of alcohol and other drug services	29	44	48
Exposure to racial discrimination	47	41	34
Money problems	54	57	49
Information about health services	23	31	31
Availability of traditional health care	42	42	30
Physical environment of the service	28	33	23
Other	6	6	6

Many people made additional comments to explain or expand on the service problems that they nominated. Several commented that some Aboriginal people are coping with multiple issues in their lives and may not always prioritise their health over other problems, and therefore may not seek help, accept diagnosis, or comply with medical/social interventions.

The reluctance of some people to access help for social and emotional wellbeing problems was linked to experience of racism, illustrated by this comment:

*'I believe the reluctance of Aboriginal people to use/access appropriate services is related to their experience of institutional racism, individual prejudice and lack of respect for Aboriginal people in general. (#579, Manager, Social and Emotional Wellbeing Team)*

Many participants commented on the need for services to be more welcoming to Aboriginal people, eg through employing more Aboriginal workers in a variety of roles and provision of regular cultural awareness training for all mainstream staff. Another highlighted the importance of promoting existing services:

*'My experience dealing with Aboriginal people are that many of the "barriers" to accessing services are perceived barriers only. Just as much a barrier but actually harder to overcome. Information about available services is more important than more services. And particular emphasis*

*placed on selling the services to the community. Spend some money on promoting what is there.'* (#542, Community Program Manager, Police)

Perceived lack of confidentiality in some Aboriginal services was identified by some respondents as a major issue impacting on use of services by Aboriginal people with mental health problems, illustrated in this quote:

*'Clients find if they go to an Aboriginal service, their personal info re health status gets back to other people through family members whereas if they go to white organisation, clients know confidentiality will be maintained.'* (#526, Mental Health Team Leader)

The need for adequately resourced mental health services, especially in country areas, was seen as particularly important, eg:

*'Government, both state and federal, need to address the issue of funding for mental health workers for remote areas. I have on too many occasions had to deal with people (both Aboriginal and non-Aboriginal) with mental health problems. The mental health team... is grossly understaffed. It is almost impossible to organise an appointment for people with mental health problems.'* (#518, Community Police).

*'I find it quite disturbing that there are not a lot of services/treatment institutions for people living outside of the city.'* (#524, Aboriginal Liaison Officer)

*'I am living/working in a remote area. The Aboriginal community are suffering a lack of delivery of many services because of lack of or poor management of funds, and the lack of funds to treat health/alcohol problems at their core, ie in the home through education.'* (#574, Police)

## **Provision of information about mental health to clients**

Two thirds of respondents said their organisations provided information about mental health (social and emotional well being) to their Aboriginal clients, either routinely (45%) or only on request (55%), depending on the nature of the organisation. The information was given in several forms: verbal (19%), written (6%) or both (75%). Verbal information included one-to-one or group counselling, community seminars, and individual referrals to mental health specialists or Aboriginal social and emotional well being services. Written information included pamphlets, posters and patient

information sheets, but these were often described as generic, and not specifically designed for Aboriginal people. Graphical information was rarely available, and verbal information in Aboriginal languages was provided only where there were interpreters, eg:

*'I do not have any pictorial material, or information in any Aboriginal languages'* (#573, Social Worker)

Some respondents wanted more or different information to give to their clients, eg:

*'I would like more culturally appropriate hand-held information' (#507, General Practitioner)*

*'We have a lack of information to give clients. Booklets and info sheet would be a good start for us, as case managers.' (#552, Community Corrections Officer)*

The majority (88%) of respondents thought the information they provided about mental health was useful to their clients and most thought their clients understood the information. When asked how they knew if their clients understood, some assumed that simply having Aboriginal health workers to provide explanations would ensure comprehension, whereas others judged understanding from client feedback, eg:

*'By asking the client to repeat what I have said, and ask them do they understand me. If not, go over it again until they understand.' (#501, Aboriginal Health Worker)*

Suggestions for improving the types and provision of information about mental health for Aboriginal people included pictorial resources and leaflets with non-medical language:

*'Make (written information) user friendly, short and simple, include pictures.' (#570, Aboriginal Health Worker)*

Other ideas included provision of information by trained Aboriginal workers with knowledge of local Indigenous languages, community and school workshops. In particular, the use of story telling with supporting resources was suggested, especially for remote areas and traditional clients with limited English literacy:

*'Story flip charts where the person giving information can speak (Aboriginal) language and just show pictures of what they are talking about, felt body narratives etc.' (#503, registered remote area nurse)*

Raising community awareness about mental health was also considered important in reducing shame and stigma associated with mental health problems and increasing the acceptance of counselling and medication interventions, eg:

*'More promotions and community awareness workshops at least every quarter.' (#537, CEO, Aboriginal community council)*

Imaginative use of mass media (TV, radio, video) and positive role-modelling by Aboriginal celebrities were other suggestions.

## **Provision of information about quality use of medication to Aboriginal clients**

54% of respondents said they, or their organisations, provided information about medications to Aboriginal clients, either routinely (65%) or on request (35%). The information varied greatly, from *'routine verbal info & brochures'* to more extensive explanations based on individual need:

*'Being careful about dosage of medication/ Taking it at specified times/ What the medication is used for e.g. why they have it, what it contains.'*  
(#534, Family support worker)

Information was given verbally (41%), in writing (5%) or both (55%). Compared to information about mental health, there was relatively more reliance on verbal information about medications, reflecting the lack of culturally appropriate written resources. Information was provided in English, with translation into Aboriginal languages (mostly Pitjantjatjara) according to need and availability of interpreters.

97% of respondents agreed that clients understood the medication information provided, and that it was useful to them. They knew that information was understood from the questions asked by the client and feedback from the client and family, and several people mentioned compliance as an indicator of understanding. Suggestions for improving the type and provision of information about quality use of medicines were similar to those described above in relation to information on mental health.

## **Major medication issues for Aboriginal people with mental health problems**

Participants were asked to nominate which of the listed issues affected the quality use of medications by Aboriginal people with mental health problems. 83 people completed this question, and the results are shown Table 3 below. It is evident that most of the listed issues were considered by 20% or more of respondents as important factors impacting on quality use of medicines by Aboriginal people with mental health problems.

**Table 3. Medication issues impacting on Aboriginal people with mental health problems**

Medication issues	Percentage of respondents nominating each issue		
	Urban	Rural	Remote
Class of medication	21	21	20
Dosage	22	30	22
Cost of prescription	42	41	31
In what form and how given	20	24	24
Assistance	24	30	22
Advice	26	26	27
Compliance	39	42	36
Information/knowledge of client about medication	33	37	36
Quality of explanation and reinforcement of medication information	31	33	25
Feelings about medication	36	39	31
Treatment orders (ie legally imposed taking of medication)	32	27	30
Sharing of medications	38	37	26
Doctor shopping	31	30	19
Drug or alcohol use	51	54	39
Non-prescription legal medications	32	25	21
Side effects	39	39	31
Inappropriate prescribing/dispensing	30	22	21
Availability of pharmacy services	19	24	21
Availability of accident and emergency services (crisis intervention)	24	24	25
Delivery of medications	20	20	22
Storage of medications	30	27	23
Disposal of medications	21	21	20
Waiting for medication	19	15	19
Safe use of medication	37	36	32
Other	6	3	2

The most frequently cited issue for both urban and rural areas was drug or alcohol use, closely followed by prescription cost, compliance, feelings about medications, sharing of medicines and side effects. For remote areas, drug and alcohol use was most commonly cited (as in urban and rural areas), with information/knowledge about medication also frequently nominated. Some participants stated that health and medication were not priority issues for some Aboriginal people.

Some illustrative comments in relation to important issues affecting quality use of medications by Aboriginal people with mental health disorders follow. For example the cost of medicines was regarded by most participants as a major barrier to quality use of medicines, particularly for people who do not

consider their health to be important compared to other problems in their lives, or for people who have difficulty budgeting.

*‘Majority of my clients run out of their medication and have to wait until the next pension/pay day until they can get their scripts filled. In the meantime they are on nil medication.’ (#520, Aboriginal health worker)*

*‘Cost of prescription major problem, pokie machine are other priorities over buying medication and may expect Aboriginal health service to pay for prescriptions.’ (#569, registered nurse, Aboriginal health service)*

For clients with major mental health disorders, lack of compliance with prescribed medications may result in treatment orders and involvement of the Guardianship Board, which can be frightening and further alienate Aboriginal clients and families from mainstream services:

*‘Sometimes treatment orders can alienate Aboriginal people, especially when they are provided by non-Aboriginal health professionals.’ (#521, Aboriginal health service coordinator)*

Self medication with alcohol or cannabis is reportedly common, but may lead to problems:

*‘Drug/alcohol use is often the preferred option of self medicating and socially acceptable.’ (#563, Coordinator, non government welfare organisation)*

*‘Mixing drugs/alcohol/medication is common and can produce unpredictable, often violent, results’ (#512, Police Drug Action team coordinator)*

Itinerant people with mental health problems have particular difficulty storing their medicines safely or maintaining a medication regime, in part due to fragmented and discontinuous service provision, as illustrated by these quotes:

*‘Many of our Aboriginal people are itinerant. It is hard to find them to ensure medication is taken. Need to ensure proper understanding of the benefits of the medication.’ (#574, police)*

*‘Availability of the medication is a huge issue in rural/remote communities, particularly if the person travels they don’t usually take their medication with them.’ (#595, Education manager, TAFE)*

Several participants believed that compliance is enhanced if medication is dispensed in Webster packs or dosettes.

## **Professional supports**

46% received assistance or support in working with Aboriginal clients with mental health problems and their medications. They included money (12%),



resources (15%), education (19%), links with Aboriginal-specific services (35%), links with other services (35%), best practice information (14%), and multidisciplinary team support (23%).

There was no association between receiving such supports and giving or managing client's medications, nor was there any association between receiving such supports and prior training in mental health, drug and alcohol, or safe use of medications. These results suggest that many people are managing or giving clients' medications without any support or training, potentially putting workers and clients at grave risk.

## **Discussion and implications**

The survey highlighted that the major health service issues for Aboriginal people with mental health disorders are related to access, availability and appropriateness of services. In urban, rural and remote locations these issues include lack of money and transport problems, and in remote areas an additional major problem was limited access to specialist services.

Reluctance to access services was cited as a major issue affecting services across all regions in SA, and was related to experiences or perceptions of racism and compromised confidentiality. These findings confirm findings from our previous research [8] and our concurrent research where we interviewed clients, carers and health workers (reports in preparation). The obvious implication is that health and related services for many Aboriginal people in SA are inadequate. Since it is well known from aggregated statistical information that Aboriginal people generally are poorer and sicker than their non-Aboriginal peers, and that social and emotional wellbeing problems are of particular concern in Aboriginal communities [1-5], it is clear that this vulnerable group is poorly served. Recent publications from other research groups echo these views [18].

According to the survey results, the major issues impacting on quality use of medications by Aboriginal people with mental health disorders are drug and alcohol misuse, cost, compliance, feelings about the value of medicines, sharing of medications and unwanted side effects. Again these findings concur with our other research from this project (reports in preparation), our previous studies [7, 8], and the work of other groups [9, 14, 19].

The survey showed that the range of workers who provide services to Aboriginal clients with mental health disorders is very wide, and includes not only health professionals, but also community workers, police, educators and others. The survey results indicate that many of these workers lack adequate training and/or resources on mental health and safe medication management, yet are required to provide advice or assistance on these matters. This has potentially serious implications for clients, their

carers and other family members who may not receive correct or timely information or help, and untrained workers may also put themselves at risk.

In direct response to this identified need for training, members of the research team and their colleagues have developed, delivered and evaluated a range of short courses (as part of our larger research program). For example an intensive 3 day course on safe medication management for Aboriginal mental health was conducted. This course was designed a variety of workers including drivers, substance misuse workers, and mental health workers, who need to know how to safely transport, handle or otherwise manage medications. Members of the research team also conduct accredited 3-day intensive drug and alcohol and mental health comorbidity courses; and specific alcohol and drug training for Sobering Up Unit, Mobile Assistance Patrol and other community workers. We estimate that more than half of the workforce of Aboriginal health services in SA attended one or more of these courses during 2002, and we will continue to promote and make them available to anyone who needs such training. The research team has also facilitated workshops in response to local issues uncovered during this research, for example regarding treatment orders and the guardianship Board, supports for carers, clinical guidelines and legal responsibilities for hospital staff in relation to Aboriginal clients, and so on.

## Conclusion

A comment from one of the survey respondents was:

*'We've got a long way to go haven't we! I'm glad you're doing this research. I hope you are able to make some use of it to benefit the community.'* (#598, Counsellor)

We believe that this research is a step in the right direction. The survey provides new, reliable and current evidence relevant to mental health services and medication management for SA Aboriginal people with social and emotional wellbeing problems. It highlights the major issues impacting on quality of care and service provision, demonstrates the wide range of health and allied workers that provide advice and assistance to these people, and uncovers workforce development needs. This survey is one component of a larger SA-wide project, in which practical strategies to address issues identified by primary research are implemented and evaluated, such as training programs and local workshops.

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# Appendix



FLINDERS UNIVERSITY  
ADELAIDE • AUSTRALIA



ABORIGINAL  
DRUG AND ALCOHOL  
COUNCIL (SA) INC.

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You are cordially invited to complete this questionnaire. It should only take about 30 minutes to fill in, either in writing yourself or over the telephone. Your responses will help us to explore and improve medication management for Aboriginal people with mental health (social and emotional wellbeing) problems in South Australia such as dementia, Korsakoffs psychosis, alcohol related or acquired brain injury, Attention Deficit Hyperactivity Disorder, schizophrenia and depression.

This project has been approved by Flinders University research ethics committee, Yunggorendi and the Aboriginal Health Council of SA. **Please be assured that all questions are voluntary, your responses are confidential, and you will not be identifiable in any report.** You are free to withdraw from the survey at any time and may choose not to answer any question.

We have posted the questionnaire, following a recent telephone conversation with yourself. This will allow you to look at the questionnaire before a research assistant contacts you to make a time to ask you the questions over the phone. If that is not convenient you can complete the questionnaire in writing and return it to Helen by post in the enclosed pre-paid envelope, or fax 08 82013410.

Thank you in advance for your participation. Please phone Helen on 08 82015587 or email [helen.murray@flinders.edu.au](mailto:helen.murray@flinders.edu.au) if you have any questions about this survey.

## General questions about you

1. What is your position or job title?
2. What is the full name of the service or organisation where you work?
3. Is this an Aboriginal community controlled organisation?  
☐ yes      ☐ no
4. Are you of Aboriginal or Torres Strait Islander descent?  
☐ yes      ☐ no
5. Does your organisation employ people of Aboriginal or Torres Strait Islander descent?  
☐ yes      ☐ no
6. Have you had any training in Aboriginal cultural awareness or safety?  
☐ no  
☐ yes (*please describe*)
7. Please describe your role within this organisation
8. Years of experience  
☐ in this role      ☐ in related roles
9. How much contact do you have with Aboriginal clients in your work?  
☐ daily    ☐ weekly    ☐ occasionally    ☐ never
10. What are your highest educational and professional qualifications?
11. Have you had any training in mental health (social and emotional wellbeing)?  
☐ no  
☐ yes (*please describe*)
12. Have you had any training in alcohol & other drugs?  
☐ no  
☐ yes (*please describe*)

## Your understanding about medications

13. How would you rate your understanding about prescribed and non-prescribed medicines?  
☐ poor                      ☐ adequate                      ☐ good
14. How would you rate your understanding about other drugs including illicit drugs, alcohol and tobacco?  
☐ poor                      ☐ adequate                      ☐ good
15. How would you rate your understanding about traditional Aboriginal medicines?  
☐ poor                      ☐ adequate                      ☐ good
16. Do you ever give clients their medications?  
☐ yes                      ☐ no
17. Do you ever manage medications for clients?  
☐ yes                      ☐ no
18. Have you received training/education about safe use of medications?  
☐ yes (*go to question 19*)                      ☐ no (*go to question 20*)
19. Please describe your training/education about medications  
(ie what, where, when)  
  
(*go to question 23*)
20. Would training/education about medications be relevant to your practice?  
☐ yes (*go to question 21*)                      ☐ no (*go to question 22*)
21. What factors have stopped you from doing training/education about medications?  
☐ cost  
☐ time  
☐ access  
☐ suitability  
☐ availability  
☐ other (please specify)
22. Why is training/education about medications not relevant to your practice?

## Major health service issues that impact on Aboriginal people with mental health problems

23. From your experience, which of the following do you think are significant health service issues for Aboriginal people with mental health (social and emotional wellbeing) problems in relation to medications (please tick as many as you like from the list).

	Urban	Rural	Remote
Health service availability			
Access to health services			
Reluctance to use health services			
Transport to/from health services			
Availability of specific services for Aboriginal people			
Availability of gender specific services			
Availability of specific services for youth			
Availability of specific services for older people			
Availability of specialist mental health services			
Availability of alcohol and other drug services			
Exposure to racial discrimination			
Money problems			
Information about health services			
Availability of traditional health care eg ngangkari			
Physical environment of the service			
Other (please specify)			

24. Do you wish to make comments on any of the above?



## **Provision of information about mental health to Aboriginal clients**

25. Do you or your organisation provide information to Aboriginal clients about mental health (social and emotional wellbeing)?  
[   ] yes                      [   ] no (*go to question 34*)
26. If so, what information is provided by your organisation to Aboriginal clients about mental health (social and emotional wellbeing) problems?
27. In what form is this information provided?  
[   ] verbal explanations              [   ] written information
28. What percentage of your worktime is spent in an average week providing information about mental health to Aboriginal clients?
29. In what languages is the information about mental health provided?
30. When is information about mental health provided to Aboriginal clients?  
[   ] routinely                      [   ] only as requested
31. Do your Aboriginal clients understand the information about mental health?  
[   ] yes                      [   ] no (*go to question 34*)
32. How do you know if your clients understand this information?
33. Do you think the information provided about mental health is useful to your clients?  
[   ] yes                      [   ] no
34. What suggestions to you have for improving the type and provision of information about mental health (social and emotional wellbeing)?

## **Provision of information about quality use of medication to Aboriginal clients**

35. Do you or your organisation provide information to Aboriginal clients about medications and medication use issues?  
[    ] yes                      [    ] no (*go to question 44*)
36. If so, what information is provided by your organisation to Aboriginal clients about quality use of medications?
37. In what form is this information provided?  
[    ] verbal explanations              [    ] written information
38. Please estimate the percentage of your worktime spent providing information about medications to Aboriginal clients.
39. In what languages is the information about medications provided?
40. When is information about medications provided to Aboriginal clients?  
[    ] routinely                      [    ] only as requested
41. Do your Aboriginal clients understand the information about medications?  
[    ] yes                      [    ] no
42. How do you know if your clients understand this information?
43. Do you think the information provided about medications is useful to your clients?  
[    ] yes                      [    ] no
44. What suggestions to you have for improving the type and provision of information about quality use of medications?

## Major medication issues for Aboriginal people with mental health problems

45. In your experience, what are the significant issues affecting the quality use of medications by Aboriginal people with mental health problems (please tick as many as you like from the list)

	Urban	Rural	Remote
Class of medication			
Dosage			
Cost of prescription			
In what form and how given			
Assistance			
Advice			
Compliance			
Information/knowledge of client about medication			
Quality of explanation and reinforcement of medication information			
Feelings about medication			
Treatment orders (ie legally imposed taking of medication)			
Sharing of medications			
Doctor shopping			
Drug or alcohol use			
Non-prescription legal medications			
Side effects			
Inappropriate prescribing/dispensing			
Availability of pharmacy services			
Availability of accident and emergency services (crisis intervention)			
Delivery of medications			
Storage of medications			
Disposal of medications			
Waiting for medication			
Safe use of medication			
Other ( <i>please specify</i> )			

46. Please expand on the 3 most important issues identified in the previous question affecting the quality use of medications by Aboriginal people with mental health problems.

## **Your professional supports**

47. Do you or your organisation receive any assistance or support in working with Aboriginal clients with mental health problems and their medication management?

☐ yes                      ☐ no (*go to question 51*)

48. Which of the following forms of supports do you or your organisation receive? (please check as many as you like from the list)

- ☐ money
- ☐ resources
- ☐ education
- ☐ links with other services
- ☐ links with Aboriginal-specific services
- ☐ best practice information
- ☐ multidisciplinary team support
- ☐ other (*please specify*)

49. Please expand on the most useful supports you receive.

50. Are there any new initiatives in the last 12 months in your area which are relevant to quality use of medicines by Aboriginal people with mental health problems?

☐ no  
☐ yes (*please expand*)

51. Any further comments you wish to make in regard to Aboriginal persons with mental health problems and their medication management.

Thank you for participating in this questionnaire.

We will telephone you to record your answers, or you may prefer to post it to Helen Murray, School of Nursing and Midwifery, Flinders University, GPO Box 2100, Adelaide 5001, or fax 82013410.

# Chapter 7

## Review of hospital separation data

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### **This chapter was prepared by:**

- Inge Kowanko
- Charlotte de Crespigny

### **Acknowledgments**

We thank Jenny Hargreaves, Naila Rahman and Narelle Grayson from the Australian Institute of Health and Welfare for providing the original dataset. The advice and practical assistance of Kylie Lange, statistics consultant at Flinders University is much appreciated.

### **Introduction**

Although it is well established that Aboriginal people are still much sicker and poorer than non-Aboriginal people, and experience high levels of social and emotional distress [1, 2], to date there has been no detailed examination of hospital morbidity data focusing on medication, substance use and related issues among Aboriginal people with mental health problems. Therefore we explored South Australian hospital separation data in light of recently published state and national aggregated health statistics.

This review of hospital data is a component of the larger SA-wide project *Better medication management for Aboriginal people with mental health problems, their carers and other family members*. It was considered with the findings from interviews and focus groups with clients, carers and workers, a survey of service providers and a review of the literature in formulating recommendations aimed at improving safe medication use by Aboriginal people with mental health problems.

### **Aims**

The purpose of the review was to explore patterns of diagnosed mental health disorders including medication and substance use problems, and associated physical health problems among Aboriginal people in relation to age, gender and location. Additionally, the pattern of injuries such as adverse drug reactions, poisoning, crashes, falls, burns, self-harm and assault associated with mental illness and substance use was explored.

## Methods

The researcher negotiated with the Australian Bureau of Statistics (ABS), National Centre for Aboriginal and Torres Strait Islander Statistics (NCATSIS) and the Australian Institute of Health and Welfare (AIHW) to obtain an appropriate set of hospital separation data for SA Aboriginal people with mental health problems. This data was strictly 'confidentialised'. To ensure that there could be no possibility of identifying anybody, some information (e.g. region of usual residence, age) was aggregated. The dataset was released to the research team only after satisfying the Aboriginal Services Division of the SA Department of Human Services that all research ethics approvals had been granted. In all, it took almost a year to obtain a complete and accurate dataset from AIHW. A modest fee was charged to provide the data to the research team.

The inclusion criteria were:

- separated from a South Australian public or private hospital during the 5-year period July 1995-June 2000;
- identified as Aboriginal or Torres Strait Islander;
- principal or additional diagnosis of mental disorder (as specified in ICD-9-CM chapter 5 [3] and ICD-10-AM chapter V [4]).

The AIHW provided the following minimum information for each hospital separation record:

- unique identifier number;
- sex;
- principal diagnosis and all additional diagnoses - the principal diagnosis is a single diagnosis deemed responsible for the client's hospitalisation. Additional diagnoses are those also recorded for that episode of hospital care;
- external cause of the principal diagnosis (where applicable and if known);
- region of usual residence - data for the region of usual residence were provided by AIHW in aggregated form. 'Statistical local area' of residence is routinely included by AIHW, but could have enabled identification of some people in the dataset, particularly in sparsely populated areas. Therefore the AIHW grouped the SA statistical local area information into 8 larger regions in SA [5]. The regions were: Hills, Mallee, Southern; Wakefield; Mid North; Riverland; South East; Eyre; Northern and Far Western; and Metropolitan Adelaide. Together these cover the whole of SA. Collapsing location data into these 8 regions was justified because they are being used in key Indigenous health reports and plans [5, 6]. Furthermore, use of these regions is in keeping with the intent of the overall research plan of the large project of which this statistical review is a part, as it provides regional health statistics information to complement our other local research activities, as well as SA-wide integration of findings;

- age - exact ages were not provided by the AIHW, again to safeguard confidentiality. Instead, each hospital separation record was assigned to an age category by AIHW. The number and width of the age categories varied between regions, with finer age categories in more populated regions (see Table 4).

The 5-year dataset contained almost 9000 eligible hospital separation records in total. Each record summarises morbidity and other data for an episode of care terminating with the patient's separation from hospital due to discharge, transfer or death. However, it should be noted that number of separations does not equate to number of persons, as some individuals would have been hospitalised on more than one occasion.

The data was sent as a series of compressed spreadsheet files that required considerable manipulation, in consultation with the research team, to combine them for overview analysis. The resulting combined 5-year dataset was large enough to provide a credible overview of hospital separations of Aboriginal people with mental health disorders in SA as a whole and in the regions, in keeping with the project's purpose.

The original data was manipulated and combined as follows. For the years 1995-1999, ICD-9-CM codes for diagnosis and external causes were provided, whereas in the years 1999-2000, ICD-10-AM codes were provided [3, 4]. As there are differences between these coding systems, the researchers mapped the diagnoses to major disease categories that were inclusive of both (see Appendices 1 and 2 at end of this chapter) in order to analyse the whole 5-year dataset at once. Also, the statistics program chosen for analysis (SPSS) could not manage the alphanumeric ICD-9-CM and ICD-10-AM codes. This problem was overcome by reducing the codes to 3 or 4 digits. Although additional, more detailed information was included in the original data from later years (e.g. location and activity associated with external cause of injury), much of it was excluded from this overview analysis.

The data were analysed using the Statistical Package for Social Sciences (SPSS) program, generating descriptive and graphical summaries. Appropriate correlation and cross-tab statistical analyses were used to explore associations between variables. Statistical significance was calculated using Pearson's chi-square test with continuity correction and the contingency coefficient. Critical values of P were conservatively adjusted for planned multiple tests using the Bonferroni correction (i.e. tests were considered statistically significant if  $P < 0.05/n$ , where n is the number of planned tests in each analysis set). No denominator data were provided to relate our findings to the total number of Aboriginal /non-Aboriginal separations with/without mental/other disorders, and so we referred to recent reports of health statistics.

## Results

During the 5-year period 1995-2000 there were 8,794 hospital separations in SA of Aboriginal people with a principal or additional diagnosis of mental disorder (mean of 1,758 per year).

The clients' usual place of residence, where known, was provided by AIHW as one of eight SA regions [5], in keeping with the overall research design of the larger SA-wide project. About one third normally lived in Metropolitan Adelaide and a similar proportion in the Northern and Far Western region (Table 1). The usual place of residence in 7% of cases was unknown (Table 1).

*Table 1. Number of hospital separations of SA Aboriginal people with a diagnosed mental disorder during 1995-2000 by region*

Region of usual residence	Hospital separations
Hills, Mallee, Southern	1106
Wakefield	327
Mid North	186
Riverland	434
South East	90
Eyre	667
Northern & Far Western	2571
Metropolitan Adelaide	2673
Unknown	609
<b>Total</b>	<b>8663</b>

Hospital separation rates of Aboriginal people with diagnosed mental disorder were also expressed as a percentage of the total Indigenous population in each region (Table 2). This was done for the year 1995-1996, only because total population estimates (based on census data) in these regions were available for that year only [5]. Examining the data in this way revealed great variability between regions in rates of hospital separations of clients with a diagnosed mental disorder. The Riverland region and the Hills, Mallee, Southern region had disproportionately high rates (18.3% and 14.5% respectively), and the Eyre region and the South East region had low rates (both less <2%). These results should be interpreted cautiously, however, because the hospital separation data and census data were collected in different ways.



*Table 2. Number of hospital separations of SA Aboriginal people with a diagnosed mental disorder during one year (July 1995-June 1996) in relation to total Aboriginal population in each region*

Region of usual residence	Population	Hospital separations	
		count	% of population
Hills, Mallee, Southern	1390	202	14.5
Wakefield	781	29	3.7
Mid North	436	28	6.4
Riverland	623	114	18.3
South East	536	9	1.6
Eyre	1741	31	1.7
Northern & Far Western	5551	548	9.9
Metropolitan Adelaide	9377	457	4.8
Unknown		134	
<b>Total</b>	<b>20435</b>	<b>1552</b>	<b>7.6</b>

There were slightly more male (54.4%) than female (45.6%) separations from hospital of Aboriginal clients with diagnosed mental disorders in the years 1995-2000 in the whole of SA. Table 3 shows the gender breakdown by region of usual residence. It indicates a similar pattern in every region.

*Table 3. Number of male and female hospital separations of SA Aboriginal people with a diagnosed mental disorder during 1995-2000 by region*

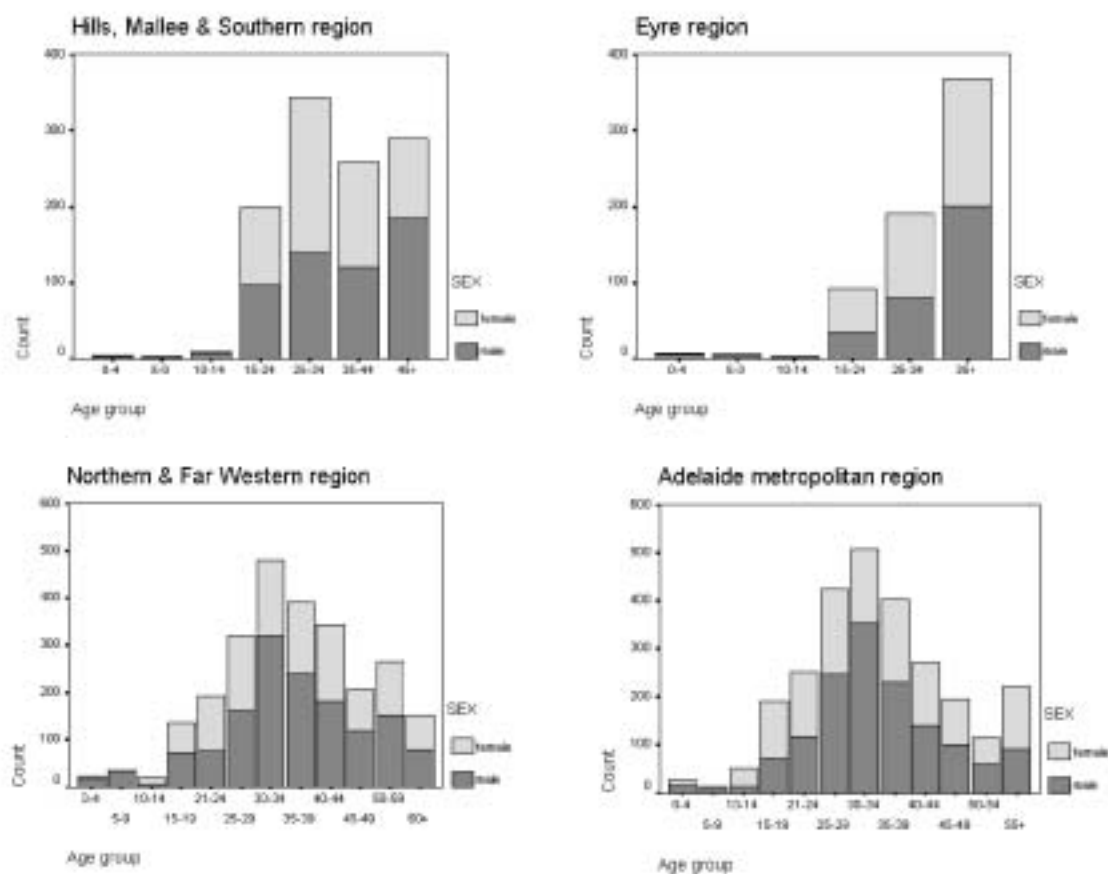
Region of usual residence	Hospital separations		
	male	female	total
Hills, Mallee, Southern	552	554	1106
Wakefield	174	153	327
Mid North	108	78	186
Riverland	246	188	434
South East	47	43	90
Eyre	327	340	667
Northern & Far Western	1468	1103	2571
Metropolitan Adelaide	1456	1217	2673
Unknown			609
<b>Total</b>	<b>4771</b>	<b>3952</b>	<b>8663</b>

It was not possible to analyse the whole-of-SA hospital separation data by clients' age. This is because exact ages were not provided for confidentiality reasons. Instead, the AIHW provided an age category for each separation, and the size of age categories differed from region to region, as indicated in Table 4. For example, separations from the Hills, Mallee, Southern region were categorised into 7 age groups (0-4, 5-9, 10-14, 15-24, 25-34, 35-44 and 44+ years), whereas in the Wakefield region they were collapsed into only 3 age groups (0-9, 10-24 and 25+ years). Table 4 shows the number of separations in each age category for each region. Figure 1 shows age and gender distributions of hospital separations of people from selected regions in SA (i.e. those with 4 or more age categories). It is evident that there were hospital separations of Aboriginal people with diagnosed mental disorders across all age groups, peaking in mid-adulthood. Males and females appear to be approximately equally represented across most age groups, although males tend to outnumber females in the 25-34 year categories.

*Table 4. Hospital separations of SA Aboriginal people with mental disorders in 1995-2000: Number of separations in each age category by region of usual residence*

Age	Number of separations							
	Hills, Mallee, Southern	Wakefield	Mid North	Riverland	South East	Eyre	Northern and Far Western	Metropolitan Adelaide
0-4 years	4	3	186	4	2	7	23	28
5-9 years	1	42	186	4	2	6	37	15
10-14 years	8					3	20	52
15-19 years	148					93	137	190
20-24 years	241	282		430	88	190	194	251
25-29 years							321	424
30-34 years							480	506
35-39 years	200					368	390	402
40-44 years	219						344	271
45-49 years							207	196
50-54 years							266	117
55-59 years							152	221
60+ years								152

Figure 1. Number of male and female separations of Aboriginal people with mental disorders in 1995-2000: Age distribution in selected SA regions



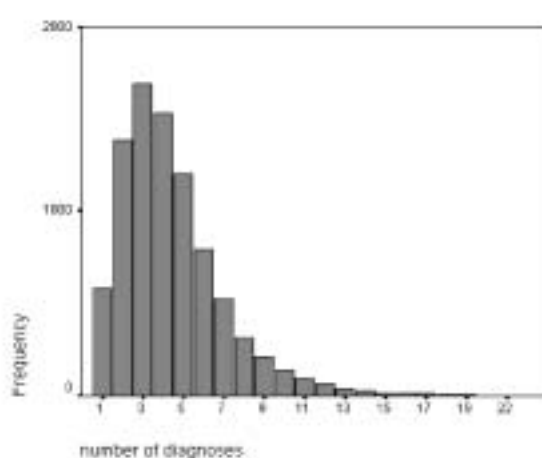
Over the period 1995-2000, numbers of hospital separations in SA gradually increased (Table 5). Analysis of the data by region showed that this gradual increase over time was evident in all regions of SA.

Table 5. Number of hospital separations of SA Aboriginal people with a diagnosed mental disorder in each year during 1995-2000

Year	Hospital separations
1995-1996	1525
1996-1997	1511
1997-1998	1737
1998-1999	1829
1999-2000	2061
<b>Total</b>	<b>8663</b>

There were generally multiple diagnoses for each hospital separation. The median number of diagnoses per hospital separation was 4, range 1-25 (Figure 2). This was observed in every region.

*Figure 2. Number of diagnoses per hospital separations of SA Aboriginal people with a principal or additional diagnosis of mental disorder*



For ease of analysis, the reserachers mapped the ICD-9-CM and ICD-10-AM codes into broad new diagnosis categories compatible with both systems (Appendix 1). The types of diagnosed mental disorders were various, but for the whole of SA 79% of records in our dataset involved dependent or non-dependent alcohol and/or drug problems (Table 6). The Riverland region had the greatest proportion of Indigenous separations with mental health diagnoses involving alcohol and/or drug use (86.6%).

In about one quarter of Indigenous separations with primary or additional diagnoses of mental health disorder across SA there was also a primary or additional diagnosis of injury, poisoning or other consequence of any external cause (Table 6), ranging from 19.6% of separations (Wakefield region) to 31.6% (Northern and Far Western). The most common of these diagnosed consequences of external causes were head injuries (9.3% of separations) and poisoning (4.6% of separations), with the majority of diagnosed poisonings due to drugs rather than alcohol. Burns were rare at less than 1%. Analysis of the data by region revealed broadly similar patterns of diagnosed consequences of external causes. However it was notable that the rate of head injury was highest in the Mid North region (16.8%) and lowest in the Wakefield region (5.3%), and that the rate of poisoning was highest in the South East region (8.6%) and lowest in the Northern and Far Western region (2.1%). Correlation and cross-tabular analysis (Table 7)

indicated that Aboriginal people whose mental disorders were related to dependent or non-dependent alcohol or drug use were significantly less likely than those with other mental disorders to have diagnoses of poisoning, and significantly more likely to have head injuries.

*Table 6. Hospital separations of SA Aboriginal people with a diagnosed mental disorder in 1995-2000 by diagnosis category*

<b>Diagnosis category</b>	<b>count</b>	<b>% of all diagnoses</b>	<b>% of all separations</b>
Mental disorders with alcohol and/or drug involvement	6139	19.1	79.1
- Mental disorders with alcohol involvement	3631	11.3	46.8
- Mental disorders with drug involvement	3172	9.9	40.8
All diagnoses of injury, poisonings and other consequences of external injury	2091	6.5	26.9
- Head injuries	726	2.3	9.3
- Burns	42	.1	.5
- Poisonings (by alcohol)	91	.3	1.2
- Poisonings (by drugs)	332	1.0	4.3
Infections and parasitic diseases	1037	3.2	13.4
Neoplasms	131	.4	1.7
Endocrine, nutritional, metabolic disorders and blood cell/immunity disorders	1965	6.1	25.3
Diseases of nervous system and sense organs	1626	5.1	20.9
Diseases of the circulatory system	1477	4.6	19.0
Diseases of the respiratory system	1639	5.1	21.1
Diseases of the digestive system	1632	5.1	21.0
Diseases of the genitourinary system	729	2.3	9.4
Diseases of the skin and subcutaneous tissue	427	1.3	5.5
Diseases of the musculoskeletal system and connective tissue	527	1.6	6.8
Certain conditions originating in the perinatal period	31	.1	.4

Most individuals suffered from multiple physical diseases and conditions in addition to their mental disorders, as indicated in Figure 2. Table 6 shows the data for all SA, and indicates that the category of diagnoses covering endocrine, nutritional, metabolic and blood cell/immunity problems was most prevalent (25.3% of separations), closely followed by diseases of the respiratory system (21.1%), digestive system (21.0%), nervous system and sense organs (20.9%), and the circulatory system (19.0%). Regional data largely mirrored the SA-wide data.

Inspection of the data, correlation and cross-tabular analysis (Table 7) indicated that people whose mental disorders were related to dependent or non-dependent alcohol or drug use were significantly more likely than those with other mental disorders to have digestive diseases and significantly less likely to have genitourinary or musculoskeletal diseases, or conditions originating in the perinatal period.

*Table 7. Hospital separations of SA Aboriginal people with a diagnosed mental disorder in 1995-2000: Statistical analyses of relationships between 'mental illness involving alcohol/drugs' and other diagnosis categories*

Diagnosis category	Test for association (a)		Test for correlation (b)		Direction of relationship (d)
	$\chi^2$	P (c)	Contingency coefficient	P	
All diagnoses of injury, poisonings, and other consequences of external injury	126.7	<0.0001	0.120	<0.0001	positive
- Head injuries	179.5	<0.0001	0.143	<0.0001	positive
- Burns	0.0	ns	0.001	ns	
- Poisoning	32.6	<0.0001	0.062	<0.0001	negative
- Poisonings (by alcohol)	13.7	<0.0001	0.041	<0.0001	negative
- Poisonings (by drugs)	36.0	<0.0001	0.065	<0.0001	negative
Infections and parasitic diseases	32.8	<0.0001	0.062	<0.0001	positive
Neoplasms	1.5	ns	0.014	ns	
Endocrine, nutritional, metabolic disorders and blood cell/immunity disorders	4.6	0.032	0.023	ns	
Diseases of nervous system and sense organs	5.0	0.024	0.025	ns	
Diseases of the circulatory system	8.0	0.005	0.031	ns	
Diseases of the respiratory system	1.0	ns	0.011	ns	
Diseases of the digestive system	190.0	<0.0001	0.148	<0.0001	positive
Diseases of the genitourinary system	21.2	<0.0001	0.050	<0.0001	negative
Diseases of the skin and subcutaneous tissue	0.2	ns	0.005	ns	
Diseases of the musculoskeletal system and connective tissue	75.7	<0.0001	0.094	<0.0001	negative
Certain conditions originating in the perinatal period	65.6	<0.0001	0.089	<0.0001	negative

(a) Pearson's Chi-square test with continuity correction, n=8663

(b) Contingency coefficient, n=8663

(c) ns: not statistically significant, i.e.  $P > 0.0029$  (NB critical value of P adjusted for multiple tests using the Bonferroni correction,  $P = 0.05/17 = 0.0029$ )

(d) Derived from inspection of the data, shown for statistically significant relationships only



Information on the nature of the external causes of principal diagnoses of injury, poisoning, etc was also provided by AIHW. In order to perform a combined analysis of the 5-year dataset, codes for external causes of principal diagnosis of injury were mapped by the researchers into new broad categories (Appendix 2). Unfortunately data on external causes of any additional diagnoses of injury were not always available across the 5 year dataset. Therefore the following analysis of nature of external causes is limited to those cases where the principal diagnosis was injury, poisoning or other consequence of external cause. We stress that this provides an incomplete picture that should be interpreted cautiously.

Table 8 shows that over a quarter of hospital separations had a principal diagnosis of injury, poisoning or other consequence of an external cause, highest in the Northern and Far Western region (32.7%) and the Mid North (31.7%), and lowest in the Wakefield region (23.6%). Self-inflicted injury and assault were named as external causes of the principal diagnosis in 4.5% and 8.1% of records respectively for all Indigenous separations in our SA-wide dataset (Table 8). Poisoning was named as an external cause of the principal diagnosis in 4.8% of the dataset. Adverse effects of therapeutic drugs was rarely named as the external cause of the principal diagnosis (only 1.2% of separations).

People with a diagnosis of dependent or non-dependent alcohol or drug involvement in mental illness were significantly more likely than those with other mental illnesses to have a recorded external cause due to assault, crashes and falls (Table 9). Cross-tab analysis and inspection of the data showed that people with diagnosed alcohol/drug involvement in mental disorder were significantly less likely to have a recorded external cause related to drugs, poisoning or self-harm (Table 9).

*Table 8. Hospital separations of SA Aboriginal people with a diagnosed mental disorder in 1995-2000 by diagnosis category*

<b>External cause category</b>	<b>count</b>	<b>% of all diagnoses</b>	<b>% of all separations</b>
All external causes	2233	7.0	28.8
All external causes involving alcohol	28	.1	.4
All external causes involving drugs	284	.9	3.7
Adverse effects of therapeutic drugs	93	.3	1.2
All poisonings	374	1.2	4.8
All suicides and self-inflicted	350	1.1	4.5
All assault	627	2.0	8.1
All undetermined if accidental or purposely inflicted	31	.1	.4
Crashes (all types of transport)	132	.4	1.7
Falls	165	.5	2.1
Drowning	3	.0	.0

*Table 9. Hospital separations of SA Aboriginal people with a diagnosed mental disorder in 1995-2000, and a principal diagnosis was injury, poisoning or other consequence of external cause: Statistical analyses of relationships between 'mental illness involving alcohol/drugs' and nature of external cause*

External cause category	Test for association (a)		Test for correlation (b)		Direction of relationship (d)
	$\chi^2$	P (c)	Contingency coefficient	P	
All external causes	122.9	<0.0001	0.119	<0.0001	positive
- All external causes involving alcohol	0.9	ns	0.013	ns	
- All external causes involving drugs	10.8	0.001	0.036	0.001	negative
- Adverse effects of therapeutic drugs	4.6	ns	0.024	ns	
- All poisonings	29.3	<0.0001	0.059	<0.0001	negative
- All suicides and self-inflicted	22.5	<0.0001	0.052	<0.0001	negative
- All assault	149.9	<0.0001	0.132	<0.0001	positive
- All undetermined if accidental or purposely inflicted	3.2	ns	0.021	ns	
- Crashes (all types of transport)	23.2	<0.0001	0.053	<0.0001	positive
- Falls	24.4	<0.0001	0.054	<0.0001	positive
- Drowning	0.2	ns	0.012	ns	

(a) Pearson's Chi-square test with continuity correction, n=2091

(b) Contingency coefficient, n=2091

(c) ns: not statistically significant, i.e.  $P > 0.0045$  (NB critical value of P adjusted for multiple tests using the Bonferroni correction,  $P = 0.05/11 = 0.0045$ )

(d) Derived from inspection of the data, shown for statistically significant relationships only

## Discussion

This review provides, for the first time to our knowledge, detailed hospital morbidity data for SA Aboriginal people with diagnosed mental health problems. The study reveals that most of these people have multiple and complex mental and physical health problems, complicated by drug and alcohol issues.

This report is unusual because we included people with any diagnosis of mental health disorder, whether it be principal or additional diagnosis. In contrast, most published reports of aggregated health statistics concentrate on principal diagnoses. They do not take account of the complexity of comorbidities. This 'silo' approach reinforces the tendency to focus on narrow specialities such as mental health, or drug and alcohol use, or

infectious diseases, and has obvious consequences for policy decisions and distribution of funding (e.g. casemix).

During 1995-2000 there was an average of 1,758 hospital separations per year in SA of Aboriginal people with a principal or additional diagnosis of mental disorder. According to recent aggregated data from the Australian Bureau of Statistics [1], these would account for about 15% of all SA Indigenous hospital separations. This is three to four times higher than previous reports that consider only principal diagnoses. For example, 4.0% and 4.4% of Indigenous separations nationally had a principal diagnosis of mental or behavioural disorder in 1998-1999 and 1999-2000 respectively [1, 2]. Given that this study was confined to hospital separation data, the true prevalence of mental disorders in the Aboriginal community is likely to be even higher, as many people do not need or want hospital treatment, or cannot access it [7]. Indeed our other research - conducted as part of the larger project of which this statistical review is a part - confirms that most Aboriginal people are affected by social and emotional wellbeing problems in some way, and that many are not formally diagnosed with mental disorders or treated in hospitals (see other chapters of this report).

There were roughly equal numbers of male and female hospital separations in our dataset. In contrast, recent national data from the ABS show much higher rates of hospital separations for adult male than female Aboriginal clients with a mental or behavioural disorder [2] (6.0% and 3.4% respectively). The discrepancy may be explained by the fact that the ABS considered only principal diagnoses, whereas our data includes both principal and additional diagnoses of mental disorder. Nationally, non-Indigenous separations with a principal diagnosis of mental or behavioural disorder were similar for males and females [2].

The data suggest that numbers of hospital separations in SA of Aboriginal people with mental disorders have gradually increased over time. It is unclear to what extent this apparent increase may be explained by changes to rates of identification as Indigenous [8], hospitalisation, diagnosis as mentally unwell, repeated hospitalisations or other factors. Aggregated national hospital separation data from the ABS suggest little change in the rate of all Indigenous hospital separations as a percentage of all separations (2.1% in 1997-1998 and 2.3% in 1999-2000), and little change in separations of Aboriginal people with principal diagnoses of mental and behavioural disorders (6% males and 4% females in 1997-1998, and 6% males and 3% females in 1999-2000) [2, 9].

This study shows that four out of every five hospital separations of SA Aboriginal people with mental health disorders also had diagnosed dependent or non-dependent alcohol and/or drug problems. This is a

disturbingly high rate, not previously reported to our knowledge. These findings confirm and extend a recent report from the ABS [2] that hospitalisation for mental disorders due to psychoactive substance and alcohol use is much more common among Indigenous than non-Indigenous people, and especially among Aboriginal males. Our findings point to the potential importance of drug and alcohol harm minimisation strategies in preventing and managing alcohol or drug related mental health problems.

This research indicates comorbidity is the norm. In addition to diagnosed mental disorders, the people in our dataset mostly had a number of other health conditions such as diabetes, renal disease and heart disease. Managing complex physical health problems as well as mental disorders is challenging for anyone, and particularly difficult for Aboriginal people who are generally disadvantaged in many ways and lack access to appropriate services. Other research that we conducted as part of the larger project confirmed this impression, and highlighted the need for coordinated services that address physical, mental and social aspects of health and wellbeing simultaneously (see other chapters in this report).

This study reveals a worrying association between mental health problems and preventable injury. About one quarter of Aboriginal hospital separations with mental health diagnoses across SA also had a diagnosis of injury, poisoning or other consequence of any external cause. Nationally, it is known that the injury and poisoning diagnoses for Indigenous people generally occur at about twice the rate of non-Indigenous people [2], but we knew of no previous published information about injuries associated with mental health problems in Aboriginal populations.

It was already known that hospitalisation due to assault, falls and self-harm were much more prevalent among Indigenous people generally than in the non-Indigenous population [2]. For this study we also examined the external causes of diagnosed poisoning and other injuries, although the findings must be interpreted cautiously because information about the nature of external causes was consistently available for principal diagnoses only. Our study showed that self-harm and assault were the most commonly named external causes of injury for Aboriginal people with mental health disorders. Interestingly, the data showed that ‘adverse effects of drugs’ was rarely named as an external cause of injury or poisoning in our dataset. The data also showed that poisoning and self-harm were less common, and assault, crashes and falls were more common for people whose mental illness involved drug or alcohol use problems than for those with other mental disorders. These data suggest that particular efforts should be made to prevent interpersonal violence, vehicle crashes and falls, targeting people with coexisting mental health and drug and alcohol problems.

This study provides new information about patterns of mental and physical health problems among SA Aboriginal people. Detailed analyses of hospital separation data in the most recent 5-year period for which data was available (1995-2000) were performed, focusing on associated drug and alcohol problems, and preventable injuries, including medication use problems.

Naturally the study has some limitations, not least because it was confined to hospital separation data and provided no information about those people who did not attend a hospital. Compromises were made in order to manage different diagnostic coding systems and other changes in the way data was recorded over the 5-year period. Confidentiality concerns meant that age and region of usual residence were collapsed into broad categories. Nevertheless, valuable new information was generated that is of potential significance to policy makers, planners and educators. Unfortunately, data on the geographical location of the hospitals was not provided, again due to confidentiality concerns, but would also have been useful for regional planning of services, especially those who cater for large numbers of clients from outside their area.

Time has not permitted more than a brief analysis of the data by region, but some interesting observations were made. For example, Aboriginal people from the Riverland region and the Hills, Mallee, Southern region separated from hospital with a diagnosed mental disorder at unusually high rates relative to their Indigenous population size. We also noted different patterns of injury in different regions. It may be possible to explore this dataset further in the future to seek other associations and possible reasons for these regional differences, and to tailor local strategies to local problems.

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*Appendix 1. Diagnosis categories used in analysis: ICD-9 and ICD-10 codes*

<b>Description</b>	<b>ICD9 code</b>	<b>ICD10 code</b>
All diagnoses of mental disorders	290-319	F00-F99
- Mental disorders with alcohol or drug involvement	291-292,303-305	F10-F19
- Mental disorders with alcohol involvement	291, 303	F10
- Mental disorders with drug involvement	292, 304-305	F11-F19
Infections and parasitic diseases	001-139	A00-A99 B00-B99
Neoplasms	140-239	C00-C99
Endocrine, nutritional, metabolic disorders and blood cell/immunity disorders	240-279	D00-D99 E00-E99
Diseases of nervous system and sense organs	320-389	G00-G99 H00-H99
Diseases of the circulatory system	390-459	I00-I99
Diseases of the respiratory system	460-519	J00-J99
Diseases of the digestive system	520-579	K00-K99
Diseases of the genitourinary system	580-629	N00-N99
Diseases of the skin and subcutaneous tissue	680-709	L00-L99
Diseases of the musculoskeletal system and connective tissue	710-739	M00-M99
Certain conditions originating in the perinatal period	760-799	P00-P99
All diagnoses of injury, poisonings, and certain other consequences of external causes	800-999	S00-S99 T00-T98
- Head injuries	800-804, 830, 850-854, 870-873, 900, 918, 920-921, 925	S00-S09, T90
- Burns	940-949	T20-T31, T95
- Poisonings	960-989	T36-T65 T96-T97
- Poisonings (by alcohol)	980	T51
- Poisonings (by drugs)	960-979	T36-T50



*Appendix 2. External cause categories used in analysis: ICD-9 and ICD-10 codes*

<b>Description</b>	<b>ICD9 code</b>	<b>ICD10 code</b>
All external causes	E800-E999	V00-V99 W00-W99 X00-X99 Y00-Y99
All external causes involving alcohol	E860	X45, X65 Y15, Y90-Y91
All external causes involving drugs	E850-E858 E873 E930-E949	X40-X44 X60-X64 X85 Y10-Y14 Y40-Y59
Adverse effects of therapeutic drugs	E930-E949	Y40-Y59
All poisonings	E850-E869 E950-E952 E980-E982 E961-E962	X40-X49 X60-X69 Y10-Y19 X85-X90
All suicides and self-inflicted	E950-E959	X60-X84
All assault	E960-E969	X85-X99 Y00-Y09
All undetermined if accidental or purposely inflicted	E980-E989	Y10-Y34
Crashes (all types of transport)	E800-E848	V01-V99, Y85
Falls	E804 E833-E835 E843 E880-E886	W00-W19
Drowning	E910, E954 E964, E984	V90, W65-W74 X71, X92, Y21

# Chapter 8

## Strategic interventions and outcomes

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**This chapter was prepared by:**

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### Introduction

Mental health disorders, alcohol and other drug problems, physical diseases and injuries, injustices, poverty, culturally inappropriate policies and practices of health and other professionals, poor access to essential services, poor communication systems, inadequate coordination of mainstream and Aboriginal services, lack of appropriate education and information, and poor supports for clients and families are all severe and unrelenting threats to the physical, cultural, social and emotional wellbeing of Aboriginal people in South Australia. The findings of the research project reported here illustrate this crisis cogently, with particular reference to medication management and mental health issues.

Although constrained by time, we have been able to offer a number of responses to these findings during the course of this research project, both locally and SA-wide. We have documented all interventions and outcomes, and evaluated them formally and/or informally if time allowed and where appropriate. Importantly, while the project has now finished, particular interventions and strategies are either being continued or will be undertaken beyond this project.

This chapter describes the various strategies, interventions and, where known, outcomes and evaluations, as well as plans and related activities that have flowed from this research. Space does not permit inclusion of detailed supporting materials such as course outlines, evaluation forms, certificates of participation, printed information resources, protocols and funding submissions.

### Approach

The approach used for this project was similar to action research, in that the research partners considered the research evidence, recommended strategies to address the issues, and implemented and evaluated selected strategies in partnership with participating groups. All these interventions, and where known outcomes and evaluations, are described in this chapter under the following headings:

- Workforce and community education.
- Improving access to, and safe management of medications.

- Coordination of services for Aboriginal people with mental health problems.
- Advocating for, and supporting ways to increase capacity of Aboriginal service providers and communities.

All were developed and applied collaboratively with our Aboriginal partners in direct response to the needs and wishes of participants, families, workers and service providers. There were also many instances where the research team responded 'along the way' to urgent issues raised by individual participants or groups of workers that required immediate attention, in keeping with the principle of prioritising participants' needs over those of the research. These additional interventions included advocacy, referral, local workshops, provision of information resources, and helping to connect organisations and groups.

Many of these strategies are still immature, yet are likely to grow and develop. This is mainly due to the willingness of the research team and our long-term collaborators to be involved over three years, and as we now know, beyond the project timeline. The depth of information revealed, and subsequent preparedness by the Aboriginal groups involved to continue to work with this team, is therefore in itself a major outcome and achievement that could not have occurred had this been a short-term project. Some of the most important achievements of the project relate to process, including our partnership model for conducting this complex multi-methods research into an extremely sensitive area - Indigenous mental health. In 2001 the research team won an award for research excellence from the Rotary International Mental Health Research Program for the pilot project undertaken in partnership with the Muna Paiendi Northern Metropolitan Aboriginal Health Service team.

The forging of inter-disciplinary and cross-organisational partnerships underpinned many of the strategies. We acknowledge the willingness of many individual colleagues and collaborating organisations in delivering professional education and training, running cultural awareness workshops, providing specialist advice, facilitating access to key services and providing information. They included: local health and social and emotional wellbeing staff from Aboriginal health services; GPs; staff of carers' organisations; hospital and community-based pharmacists; local mental health professionals; Adelaide-based personnel from the Public Advocate and Guardianship Board; nursing and medical colleagues from Flinders University Faculty of Health Sciences and the Department of Psychiatry at Flinders Medical Centre; SA Mental Health Services; City Homeless Assistance and Services Team; Nursing Services; Country Outreach Services and the Harm Reduction Education Team of the Drug and Alcohol Services Council; and staff and consumers from the Hepatitis C Council of SA. In

many instances none of these groups had worked together before, but they are continuing to do so now in relation to this research and other activities.

## **Workforce and community education**

Based on the findings in local areas and the expressed needs of participating Aboriginal communities and workers, a range of workshops and intensive training programs was developed and delivered by this team throughout the life of the project. The education programs were delivered and evaluated during 2001, 2002 and the first half of 2003, and continue to be available.

### **Local workshops for workers and community leaders**

Local workshops were offered in response to specific requests from service providers or workers in contact with the project. Aboriginal and mainstream health and community workers attended. The half- and one-day workshops were held in Adelaide, Coober Pedy and Port Lincoln. These were:

#### ***Cultural safety training for researchers***

Training in cross-cultural awareness was provided as a half-day and then a one-day workshop for the team early on in the project. Participants were our entire Aboriginal and non-Aboriginal research team members, and other academics working in Aboriginal research areas that wished to take part. Aboriginal and non-Aboriginal experts facilitated these workshops at Flinders University.

#### ***Coober Pedy cultural awareness workshop***

The Aboriginal project coordinator of this research team facilitated a half-day cultural awareness workshop in Coober Pedy. All participants were from Coober Pedy services and included Aboriginal health staff, management, social and emotional well being staff, domestic violence staff, 'bringing them home' staff, substance misuse staff, and non-Aboriginal general nurses, local hospital and FAYS managers, a GP and the community mental health outreach nurse.

#### ***Cultural safety education for undergraduate nurses***

The integrated curriculum in the School of Nursing and midwifery, Flinders University has incorporated cultural safety as a core element throughout the three years of the undergraduate nursing course. First and second year students are specifically exposed to Aboriginal health issues, including social and political aspects, primary health care and culturally appropriate care. In a second year, students undertake two fictitious Aboriginal case studies (one as part of their major assessment) that entail an holistic approach to nursing practice, incorporating cultural safety and complex care. Students are required to reflect on their own values, beliefs and morals, and develop strategies to overcome communication barriers to

effective nursing care of Indigenous people. In 2002, the chief investigator and the Aboriginal Project Coordinator provided a lecture/workshop informed by this research to all second year undergraduate nursing students.

#### ***Alcohol and other drug use workshop***

Half-day alcohol and other drug use workshops were held in Coober Pedy and Port Lincoln for Aboriginal health workers, substance misuse workers, and mental health and general health workers including local medical, nursing and social work personnel. The workshops were delivered by the research team and supported by local drug and alcohol and Aboriginal project staff. The programs focused on: psychoactive drugs and effects; spectrum of drug problems; safe care of intoxicated people; withdrawal; environmental, social and psychological determinants of alcohol and other drug problems; and referral linkages and range of treatment programs. Aboriginal-focused and mainstream resources, health promotional materials and clinical guidelines were distributed.

#### ***Port Lincoln workshop on Guardianship Board***

A major finding in the Port Lincoln region was that workers, clients and family members wanted a better understanding of the aims, roles, practices and legalities of the SA Guardianship Board and the Public Advocate in relation to Aboriginal people with mental health disorders. Clients and families were unaware of their rights in relation to their involvement with these bodies and the rules that impacted on them, such as Treatment Orders for medications for people with severe mental health disorders. They wanted information about Aboriginal representation on the SA Guardianship Board and its staff. A workshop was therefore held in direct response to these expressed needs.

Participants were local Aboriginal health and social and emotional wellbeing workers, substance misuse workers, general nurses, managers, mental health staff and others. The researchers and staff of the local mental health team delivered the program which included a videoconference with the chairperson of the SA Guardianship Board and a senior social worker from the Office of the Public Advocate. The Port Lincoln Hospital provided the videoconference facility free of charge. The videoconference enabled discussion, questioning and clarification regarding client and family members' rights, the role of local mental health workers, rationale for clients being removed to Adelaide at times of crisis, and how families can be protected from clients who are angry when being placed on repeat treatment orders. The local mental health team was provided with new information about ways in which they could better assist their local clients who were under Board-imposed psychiatric care by a designated Adelaide-based psychiatrist.

As a result of a local workshop run through this project, the Port Lincoln Community Mental Health team have reviewed their own roles and practices in relation to caring for their clients who are on Treatment Orders and must be treated by designated psychiatrists in Adelaide. They are pursuing more coordinated and locally appropriate methods of caring for these clients. As a result of the workshop, the Guardianship Board and the Public Advocate's Office have become aware of the need for better education and support for Aboriginal workers and community members regarding the roles and practices of these bodies, and have since indicated that they are following these issues up. In addition, these issues have now been included in the mental health and alcohol/drug comorbidity course delivered by members of this team from Flinders University.

## **Health information for community members and workers**

### ***Printed resources***

Most Aboriginal health services and other organisations with whom we worked lacked adequate health information resources, particularly relating to mental health and alcohol and other drug use, and safe medication use, so we provided such materials whenever we could. Written, and if available pictorial information resources were provided to Aboriginal and mainstream health and community services, GPs, local hospitals, and community groups in Coober Pedy, Port Augusta, Port Lincoln, Maitland and Adelaide. The information was in the form of posters, pamphlets, stickers, videos, newsletters and journal articles. Wherever possible we used information designed specifically to meet the needs of Aboriginal people. However, there was a dearth of accessible, culturally and linguistically appropriate information on matters relating to mental health, social and emotional wellbeing, and safe medication use.

By special invitation to key Aboriginal conferences and community expos, the research team provided a range of innovative health education resources designed specifically for Aboriginal people on topics including petrol sniffing, dementia, cannabis, alcohol, diabetes, eye care and asthma, as well as information about this project. These were presented at:

- SA Aboriginal Health Workers Association Convention, Pika Wiya Aboriginal Health Service, Port Augusta 2001.
- The Aboriginal Drug and Alcohol Council (SA) Annual General Meeting and 3-year strategic planning meeting, Parks Community Health Centre, Adelaide 2001.
- SA Aboriginal Health Workers Association (SA) meeting, Adelaide 2003.
- 'Healing the Spirit' National Substance Misuse Conference, Adelaide 2003.

Staff from SA Rural and Remote Mental Health Services are using our pilot report of this research conducted with the Muna Paiendi Aboriginal Health Service [1] as a major teaching aid. They use the report to describe mental health problems of Aboriginal people, including what it feels like for Aboriginal clients to have a mental health problem, and how Aboriginal people feel about their suffering from mental illness. This has assisted in educating mental health workers about the issues, demystifying the problems and reducing stigma.

#### ***Face-to-face information giving***

Significant time was spent with Aboriginal Elders groups and Women's groups in Reynella, Semaphore, Port Augusta and Maitland in response to their requests for a range of information on matters relating to mental health disorders, drug and alcohol problems, medicines, diabetes, hypertension, anaemia, helping family members including children and adolescents with drug and alcohol and mental health problems, and accessing key services. These groups preferred that we meet directly with them rather than them being with other groups or having a presence on our local steering committees. We continue to interact with these groups, responding to their requests to visit and provide information and guidance on safe medication use, mental health and related matters.

#### ***National Aboriginal community radio***

An opportunity arose to inform Aboriginal communities all over Australia by radio about safe medication use and mental health issues. The chief investigator was interviewed at a peak broadcasting time on Aboriginal community radio. This was in response to a direct request by the broadcaster, who was aware that the SA Minister for Aboriginal Affairs and Correctional Services, the Honourable Terry Roberts, was launching the local Port Augusta report as a component of this project.

#### ***Political influence***

By reporting the findings and key recommendations progressively, we have attracted the attention of the SA Minister of Aboriginal Affairs and Correctional Services, the Honourable Terry Roberts, regarding the urgency of the issues at hand. The Minister launched our pilot report in October 2001, and stated that he wished to be kept informed about, and wanted to launch all subsequent community reports of our research. He then launched the Port Augusta report in March 2003 and the Port Lincoln report in June 2003. The Minister has taken it upon himself to advise the SA Attorney General and SA Minister for Health of the project and its findings and recommendations. Through his direct involvement at the community level he has been in contact with many of the Aboriginal community members, workers, service providers and leaders who were involved, and given them the opportunity to relay their concerns to him first hand. He has offered his

further support by offering to launch this final comprehensive SA report and its recommendations.

### ***Publications***

We have presented our work to our colleagues and peers as opportunities arose during the project, including the following conferences. In keeping with our commitment to Indigenous capacity-building as part of this project, we sought additional funds to enable Aboriginal members of the team to attend and co-present, and this was achieved for an international conference in Canada and a national conference in Canberra.

- de Crespigny C and Cruse, S: *Better medication management by Aboriginal people with mental health disorders and their carers*. University of Adelaide and DASC Comorbidity Symposium, Glenelg, Adelaide 2001.
- Cruse S, de Crespigny C, Parfoot W, Roberts G, Wilson S, De Bellis A, Kowanko I: *Quality use of medications project: Problems associated with the use of medication by Indigenous people with social and emotional wellbeing issues and their carers*. 'Health care in a complex world': An international research conference, Toronto, Canada, May 2001.
- de Crespigny C, Wilson S, Kowanko I, De Bellis A, Cruse S, Parfoot W, Turner M, Murray H: *Better medication management by Aboriginal people with mental health disorders and their carers*. National Medicines Symposium: Linking people, actions and policy for quality use of medicines, Canberra, March 2002.
- Kowanko I, de Crespigny C, De Bellis A, Murray H, Groenkjaer M, Wilson S, Parfoot W: *Better medication management for Aboriginal people with mental health disorders and their carers*. 'Making a world of difference', First International Alcohol, Tobacco and Other Drugs Conference for Nurses & Midwives, April, Adelaide 2003.
- Kowanko I, de Crespigny C, Murray H: *Better Medication management for Aboriginal people with mental health problems, their carers and families*. 'Uncharted Territory' Conference: exploring links between chronic disease, mental health and alcohol & other drugs, Darwin, May 2003.
- de Crespigny C and Kowanko I: *Prescribed medication - use and problems. An action research project to improve medication management by Aboriginal people with mental health problems, their carers and family members*. 'Healing The Spirits' - 2nd National Conference of the Indigenous Substance Misuse Council, Adelaide May 2003.

We have already published separate reports of our pilot study in Northern Metropolitan Adelaide [1], our research in the Port Augusta [2] and Port Lincoln regions [3], and the survey of service providers [4], and these are also included in the body of this comprehensive final report of the whole project. If funds are obtained we intend to publish the findings in other formats, especially for dissemination into the Aboriginal communities. A number of papers for health journals are in preparation.



## **Professional education programs**

Two and three-day intensive professional education courses were delivered as part of the project in Adelaide, Port Lincoln and Port Augusta. They were provided to a range of workers from Aboriginal and mainstream health, social work, education, drug and alcohol, mobile assistance and sobering up, correctional and community mental health services in metropolitan, rural and remote areas of SA. Flinders University formally approved these education programs and offered articulation pathways into further education within the vocational education sector (TAFE) and tertiary postgraduate programs offered by Flinders University. These programs continue to be available. Two Aboriginal workers have engaged in formal postgraduate alcohol and other drug studies through their direct contact with this project (one has already graduated). All participants of the intensive programs received certificates of participation, which identify the total number of hours of training and a synopsis of topics covered, to be used for recognition of prior learning and credit transfer purposes in formal professional and specialist education programs.

Approximately 120 Aboriginal and non-Aboriginal workers participated in one or more of the intensive education programs provided through this project. Participants were health workers, mental health workers, nurses, GPs, managers, substance misuse workers, mobile assistance workers, social and emotional wellbeing workers, counsellors, drivers, welfare and community workers, managers, educators, correctional services workers and enrolled postgraduate students. All were directly or indirectly in contact with the project. Over one third of the total number of Aboriginal health workers in SA undertook at least one of these programs, all without fees. Their employers supported all participants in attending the programs, representing a significant commitment to the issues by service providers. This was especially significant for rural and remote area services, where many of the Aboriginal workers and others are needed to deliver essential services. It is difficult or impossible to replace these people while they are away for training.

### ***Safe management of intoxicated people and clean needle and syringe program***

As a result of being involved with the research project, the manager of Port Augusta Substance Misuse Service specifically requested this training for all mobile assistance and sobering up staff. In addition, there were participants from Port Lincoln Aboriginal Health Service and Umoona Tjutagku in Coober Pedy. The course was a 3-day intensive program, and its aims and curriculum were designed in consultation with service providers. It was delivered in 2002 in Port Augusta by the chief investigator and staff from the Harm Reduction team of the Drug and Alcohol Services Council of SA and Hepatitis C Council of SA. The 16 workers who took part earned certificates

of participation in the overall program as well as becoming bona fide Clean Needle and Syringe Exchange Workers under the Drug and Alcohol Services Council and SA Department of Human Services Clean Needle and Syringe Accreditation Training scheme, for which they received an additional certificate.

Participants were invited to complete written evaluation questionnaires immediately after the course and again four months later. Immediately after the course participants (94% response rate) rated its quality and relevance highly and said they would recommend it to others. They had a better understanding of work-based occupational health and safety issues, in particular risks associated with hepatitis C and workplace hygiene, including the management of intoxicated clients. All said they would use their new knowledge gained from the course for their work, particularly in regard to giving accurate advice to clients. Respondents to the follow-up evaluation (38% response rate) said they had retained much of the new knowledge, and made changes to their work practices and protocols. Based on 'word of mouth' in the Aboriginal community and the growing reputation of this team in its ability to deliver practical quality education, further discussions are now being held with other Aboriginal services for this program to be delivered in Adelaide to sobering up, mobile assistance and hostel workers in the near future.

### ***Safe Medication Management in Community Settings***

This program was developed in response to this research project's qualitative and survey findings that few workers from health and community-based services (including police) have been trained in safe management of medicines, despite being frequently called upon to provide, transport, store or administer medications to their clients. We identified a previous training program that had been delivered through Northern Territory Health and the Flinders School of Nursing and midwifery to registered Aboriginal health workers in Central Australia (Taylor, K 2001). Members of this team, and specialist pharmacist and nursing academics, refined and adapted the program to suit the topic of Aboriginal mental health and medication management in the community in SA. This team delivered the program initially in 2002 as a 3-day intensive (Safe Medication Management: Aboriginal Mental Health) at Flinders University. This course was modified in light of feedback from the first course and delivered again as a 2-day intensive in 2003 (Safe Medication Management in Community Settings) at Nunkuwarrin Yunti Aboriginal Health Service in Adelaide. The second program was shortened to facilitate access for workers from short-staffed services. Both programs were delivered by members of the research team in collaboration with a specialist mental health nurse, experienced remote area nurse and pharmacist, all of whom had experience in teaching Aboriginal workers. Participants came from Port Lincoln, Coober Pedy, Ceduna and

various metropolitan areas of Adelaide. They were drivers, social and emotional wellbeing workers, substance misuse workers, counsellors, sobering up workers, mobile assistance workers and nurses from a range of Aboriginal health and community-based services. The manager of the Substance Misuse Services in Alice Springs attended expressly at our invitation so that he could then deliver the program to workers in Alice Springs and remote communities in Central Australia. He has since been undertaking this. All participants were provided with a specifically designed workers' manual as a key resource and a certificate of participation. Flinders University has approved the program as a continuing education course.

Fifteen people attended the first course in 2002. Participants were invited to complete written evaluation questionnaires on completion. The response rate was 80%. They found the course relevant to their work and praised the presenters. Nearly all said they gained a better understanding and awareness of key issues and that they would make changes at work. Their ideas included: putting on more trained staff, providing more staff education, explaining medications better to clients, monitoring clients' medication use more, improved labelling of medications, advocacy for clients in relation to prescribed medications and including a medication regime in all client health assessments.

Ten people, some Aboriginal and some non-Aboriginal, attended the second course. Evaluation questionnaires were handed out on the last day. Seven were returned (70% response rate). Most said they would recommend the course to others with similar roles and wanted it recognised as part of a formal study program. All reported that the course increased their understanding of key issues and that all the sessions were useful. They reported the intention to make changes to their practice but did not give details. Several participants mentioned that the lectures were tiring and that there was a lot of information for a 2-day course. (Note this was originally a 3-day course, compressed into two days in an attempt to make access easier for workers from short-staffed services, based on feedback. We will continue to refine the course in light of feedback). Several people made useful suggestions, such as 'have more interactive sessions', 'give refresher courses', 'include Aboriginal presenters with direct experience of mental health problems' and 'deliver course in remote areas'.

#### ***Alcohol and Other Drugs, and Mental Health Comorbidity***

This program was delivered as a 3-day intensive on two occasions. In June 2002, the Port Lincoln Aboriginal Health Service hosted the course in Port Lincoln. Aboriginal health workers, substance misuse workers, men's workers, social and emotional wellbeing workers and non-Aboriginal nurses, postgraduate students, social workers, mental health and drug and alcohol workers, Centrelink staff, educators and correctional services workers

attended. They came from Port Lincoln, Coober Pedy, Ceduna, the Riverland and metropolitan Adelaide. The program was developed, delivered and evaluated by this research team in collaboration with specialist academics, psychiatrists and nurses from Flinders University and Flinders Medical Centre, Drug and Alcohol Services Council in Adelaide and Port Lincoln, staff of Port Lincoln Community Mental Health Services, Adelaide-based SA Mental Health Services, and Aboriginal social and emotional wellbeing staff. This program is an accredited postgraduate topic of the Flinders University Graduate Certificate in Health - Alcohol and Other Drug Studies. The 17 participants who completed the course in Port Lincoln were invited to fill in evaluation forms on completion and again 5 months later. Response rates were only 47% and 12% respectively. However, all responses were positive, with participants rating the quality, content and relevance of the program highly, and recommending it to others in similar fields. They all reported increased knowledge and understanding of key concepts related to social and emotional wellbeing, medications for mental health, drug/alcohol problems, how medicines work, safe management of medicines, legal issues, and rights and responsibilities of clients and workers. Another positive benefit was the increased sense of worth that workers felt when they understood the importance and responsibilities of their roles. Participants were planning changes in their work practices, such as being more sensitive to cultural issues and collaborating more effectively with other service providers.

In February 2003 the second course was delivered at Flinders University, Adelaide. Thirty participants completed the Adelaide program.

### ***Research skills training for Aboriginal research assistants***

A total of 8 research assistants, 6 of whom were Aboriginal, were employed and provided with individualised, on the job training as part of this project. They were selected in consultation with the participating Aboriginal communities and came from Port Augusta, Coober Pedy, Riverland, Port Lincoln and Adelaide. Up to 12 hours of research skills training was provided for these staff, individually tailored according to their experience in purposive sampling, engaging participants, confidentiality, informing potential participants about the study aims and processes, gaining and recording informed consent, data collection, interview skills, recording interviews, secure data management, data transportation, assisting in interpretation of qualitative data with analyst, team work, debriefing and care of self, advocacy and referral of participants in need. All were provided with certificates of participation as proof of their involvement so they could provide these for recognition of prior learning should they wish to gain credit or acceptance into further studies.

## **International conference**

Through exposure to this project over 20 managers, Aboriginal health workers, enrolled nurses, midwives and registered nurses who provide services to Aboriginal people and others living in rural and remote SA were supported to attend the First International Nursing and Midwifery Alcohol and Other Drugs Conference in April 2003. The SA Minister for Health, the Honourable Lea Stevens, provided bursaries and in addition, their employers who released them to attend for three days made a major contribution by paying salaries while they were absent from work. In many instances the employers also paid for travel and living expenses. Many of these workers had never been to an international conference before and found that even though the context of their practice and the nature of the issues they faced were unique and very demanding, they were able to meet other Aboriginal and non-Aboriginal colleagues who shared their concerns and knowledge, and with whom they could relate. It was thus clear that this professional development opportunity had a major effect in lifting their spirits through engaging with international and local colleagues from the USA, UK, Denmark, Japan, New Zealand and all states of Australia.

## **Future planning for education**

This research highlighted the urgent need to provide high quality, accessible education to the various components of the workforce dealing with Aboriginal clients in order to increase the capacity of workers and services to address the range of problems associated with mental health disorders, drug and alcohol problems, and unsafe medication use among Aboriginal people. There is also an urgent need for community education to raise awareness and understanding of these issues.

### ***Continued access to quality education***

Members of this team and other partners will provide continued access to quality formal and informal education, advice and information resources for Aboriginal health workers, community workers, drivers, sobering up and mobile assistance workers, mental health workers, police, corrections staff, and others assisting Aboriginal people with mental health, drug and alcohol and medication use issues. This will be through the auspices of Flinders University and its education and training collaborators, including Aboriginal Drug and Alcohol Council (SA), Aboriginal Health Council of SA, Drug and Alcohol Services Council of SA, National Centre for Education and Training on Addiction, Spencer Institute of TAFE and the Adelaide Central Mission. Strategies will include facilitating linkages and pathways into specialist mental health and drug and alcohol education programs of Flinders University, and accredited vocational education programs, as well as special programs e.g. SA Police Drug Diversion Initiative. A consortium led by this project's chief investigator is providing Accredited Worker Training.

### ***Aboriginal Health Council of SA***

As a direct result of its involvement in this research project, particularly the professional education programs delivered by this team to Aboriginal workers, the Aboriginal Health Council of SA has started discussions and planning for a partnership with Flinders University for future delivery of high quality courses for Aboriginal workers. This will be in the topic areas of drug and alcohol, mental health and safe medication management. This initiative will further strengthen the opportunities for professional development and new specialist career pathways for Aboriginal health workers and others. It will provide access to a range of quality vocational and postgraduate education opportunities that are promoted and supported by the peak Aboriginal community controlled health organisation in this state.

We have also applied for funds through the Rural Health Support, Education and Training (RHSET) Program and elsewhere to deliver such education programs in the rural/remote regions. These initiatives are part of broader collaborative links between Flinders University and the Aboriginal Health Council of SA, such as the new memorandum of understanding between these parties, and joint funding submissions focusing on Indigenous capacity building. These broader collaborative links have built on the success and respectful partnerships of this research project and related efforts from our Flinders' colleagues.

Members of the research team from Flinders University are committed to providing safe medication management training in the future (Safe Medication Management Training for diverse workers in SA, Safe Medication Education and Aboriginal Mental Health Resources for Aboriginal Communities in SA). We have also developed a proposal for community and workforce education for Aboriginal mental health.

### ***Aboriginal Health Workers Association of SA***

Discussions are about to begin with the newly formed Aboriginal Health Workers Association of SA on how this team can advocate for and support members' professional development in practice areas such as mental health, alcohol and other drugs, and safe medication management.

### ***Support networks for workers***

It is intended that collaborative efforts will be made to ensure that isolated workers will have greater access to education programs and quality information. Currently we are aware that such groups are experiencing isolation and poor access to education. Thus, viable career pathways include: Aboriginal Hospital and Community Liaison Workers; Sobering Up and Mobile Assistance Workers; Substance Misuse Workers; Crisis Intervention Workers; Women's Support Workers; Domestic/Family Violence Workers; Men's Group Workers; Youth Workers; Counsellors; Drivers;

Outreach Workers; Nutrition Program Workers; Hostel and Shelter Workers. Many of these groups came to our attention through the research processes, and were invited and assisted to attend our education and information programs. They informed us of their isolation issues, and their need to be well supported in their daily work and future education opportunities. Discussions have now begun with the Aboriginal Sobriety Group of SA to work together to provide a statewide forum for these workers to come together to share ideas and problems, receive information and education, gain access to dedicated Elder mentors and other leaders who can provide guidance and personal support to these valuable workers in their day-to-day work. This forum will be undertaken through the application of 'culture' and will be the first of many such programs in the future.

#### ***Support networks for carers***

The Port Lincoln Aboriginal Service and Port Lincoln Carers Association have formed a partnership to facilitate and support the first Aboriginal Carers' group, which now meets regularly at the Port Lincoln Aboriginal Service. This is a direct outcome bringing these services together during this project, and is going some way to meeting the needs of overburdened Aboriginal carers and other family members. In addition, Port Lincoln Aboriginal Service now has a contract with Home and Aged Community Care (HACC) to provide paid Aboriginal Carers to go into the homes of Aboriginal families caring for a person with mental health problems. This is a direct outcome of this project and a model for other similar communities.

## **Improving access to, and safe management of medications**

### **Access to essential medicines**

One of the findings of this project was that Port Lincoln Aboriginal Health Service (PLAHS) in particular had long been grappling with the problem of not being able to supply essential medicines free of charge to impoverished clients in a timely manner. PLAHS had tried to gather information about the rules and applications of the S100 scheme under the Pharmaceutical Benefits Scheme, being aware that other similar Aboriginal Health Services with comparable client profiles, such as Pika Wiya in Port Augusta, had access to this scheme. However, the Board and Management of PLAHS, despite making many inquiries, had not been able to resolve this problem satisfactorily, so that some clients continued to go without their essential medicines, compromising their health. The research team clarified the eligibility criteria for S100 for PLAHS through facilitating discussions between the researchers, PLAHS management and the Chief Pharmacist of the SA Department of Human Services. Once it became clear that PLAHS was not eligible for S100,

but that the issue still needed to be resolved, the research team linked PLAHS with the pharmacists of Port Augusta Hospital to seek their advice and guidance in establishing a better system for their clients using existing resources and services of the community pharmacist and GPs. One idea explored at the time of writing was for PLAHS to subsidise the costs of medicines dispensed at nearby pharmacies for certain clients who might not obtain and take their medicines otherwise. There is already a similar arrangement in Port Augusta where the GP marks the prescription with a 'red dot' sticker for certain clients, indicating to the prescribing pharmacist that the Aboriginal Health Service will subsidise the cost, encouraging patients to fill their prescriptions.

As revealed by our pilot study for this project [1], this also has been a longstanding issue for Muna Paiendi Aboriginal Health Service in Northern Metropolitan Adelaide. Muna Paiendi has since partially addressed the problem through negotiated arrangements involving financial assistance via Nunkuwarrin Yunti Aboriginal Health Service in Adelaide and a particular local pharmacist. Through this project involvement, the Riverland pharmacist and Aboriginal hospital liaison officers are advocating for, and facilitating safer medication use amongst Aboriginal clients and their families.

## **Safe medication transportation**

Aboriginal drivers and community workers in rural, remote and metropolitan areas of SA are employed to provide transport for their clients' various services, including to and from doctors' appointments and the local pharmacy, the hospital and other places. They are also frequently required to deliver medicines to clients at home or elsewhere. The PLAHS drivers attended the first three-day intensive 'Safe Medication Management: Aboriginal Mental Health' course in 2002 as part of this project, and this raised their awareness of the importance of their role in safe medication management. They told how they often worried overnight or over the weekend about their clients experiencing anger, grief, money worries, depression associated with medical diagnoses, racism, intoxication, acute illness and suicidal ideation. Drivers were also concerned about the legal and safety implications of holding medications over weekends if a responsible adult was not at home to receive them late on Friday afternoons.

These drivers were proactive in addressing these unsafe practices and concerns in collaboration with the research team and local service providers, and as a result several new strategies are now in place. A weekly debriefing process on Friday afternoons, with extra sessions ad hoc, has now been instigated between the PLAHS drivers and their direct supervisor. The 'Port Lincoln Aboriginal Health Service Drivers' Protocol for Safe Handling of Medication' is now in place. This was developed collaboratively by the



research team, PLAHS drivers and management, and the local community pharmacist. Importantly, it incurred no additional financial outlay for PLAHS or clients. The protocol covers practical, legal and safety aspects of handling, storing, transporting, and giving medications. It includes practical strategies such as keeping medicines cool in a foam container in the car boot. This protocol will guide other groups and will be included in the newly developed SA-wide 'Rural/Remote Driver and Community Worker Safe Medication Transportation Education and Procedure Package' that we hope will be funded by RHSET later in 2003. PLAHS and other drivers will be key advisors to this training and related resource development (e.g. community education safe medication flipcharts; exemplars for local service policies; audio-tapes and other innovative resources), having being directly involved in putting in place improved and safer procedures and agreed arrangements for the safe collection, transportation and delivery of medicines to clients' homes.

The collaboration between the research team, local service providers and drivers to collectively address unsafe medication transportation is a model of how immediate improvements can be achieved with minimal consumption of precious time and finances. We believe that other issues may also be addressed in this way, bringing key partners together to work proactively and willingly on a problem together.

## **Coordination of care for Aboriginal people with mental health problems**

### **Inclusion of mental health and safe medication use in regional health plans**

As a direct outcome of their involvement in this project, and continuing commitment to systematically addressing the key issues uncovered by our research, PLAHS and Muna Paiendi have both included Aboriginal mental health, drug and alcohol, and safe medication use in their regional plans, business plans and work programs. They have utilised their engagement in the regional health services planning and Aboriginal Primary Health Care Access Program planning as key mechanisms for this to occur.

### **Developing a model for coordinated Aboriginal mental health care and safe medication use in rural/remote SA**

A major finding of our research in each of the SA regions was poor integration of mental health and other services. This places clients at unnecessary risk, and makes it very difficult for workers, families and

carers, who struggle to do their best in a complex health care environment with overlapping yet uncoordinated services that do not communicate effectively and which fail to focus their efforts on the patient holistically. As a result of this major concern, a new project has been developed as a collaborative partnership between PLAHS, Flinders University and Eyre Division of General Practice (EDGP). It has already received seed funds from Flinders Institute for Health Research and joint planning has begun. It is intended that the model will develop a viable process for coordinating the care of Aboriginal people with mental health problems, and medication use issues for the whole Eyre Region. We will work across sectors and bring about systemic change across rural/remote and metropolitan services responsible for the care of these people and their families. Key personnel involved in the three organisations all have significant experience in delivering Aboriginal and non-Aboriginal mental health and alcohol/drug care, general medical practice, health services management and research including conducting coordinated care trials. It is hoped that further funds will be forthcoming and a viable model will develop for other regions within and beyond SA.

### **Other coordinated care initiatives**

Flinders University is now participating in a number of large initiatives involving coordination of care for Aboriginal people with chronic diseases, including mental illnesses. These initiatives include the new Cooperative Research Centre for Aboriginal Health in which this research team and other Flinders researchers have key roles, and the proposed Centre for Clinical Research Excellence in Aboriginal Health, a joint submission from Flinders University (including members of this team) and the Aboriginal Health Council of SA.

### **Advocating for, and supporting ways to increase capacity of Aboriginal service providers and communities**

#### **Informing services of government initiatives relevant to Aboriginal mental health and safe medication use**

During this project, a number of funding sources were identified that could be channelled into better services for Aboriginal mental health including safe medication use. Some of these were not widely known by Aboriginal service providers. For example, the Practice Incentive Program enables general medical practices and Aboriginal health services to access special

funds from the Health Insurance Commission to employ registered nurses and Aboriginal health workers [5]. We informed the Aboriginal Health Council about the Practice Incentive Program but they were not aware of it. Now that it has been brought to their attention they will survey their member organisations (community controlled Aboriginal health services) about their knowledge and use of these funds, and promote the program.

In the course of this project we explored the S100 scheme, which enables some remote Aboriginal Health Services to keep a limited range of essential medicines on site, purchase these at Pharmaceutical Benefits Scheme rates and dispense them to needy clients at no charge. The savings may be used to improve quality use of medicines, as in the Tiwi Islands for example, where this scheme has been used to pay for a pharmacist to make Webster packs and provide community education [6]. Although there are some reservations about whether the S100 scheme improves medication management in all situations [7], some of our participating organisations showed strong interest. The research team helped them clarify their eligibility for the scheme and explore alternative options.

Muna Paiendi told us of a 30% loading paid to SA public hospitals and certain general practices for their Aboriginal clients, and how it is difficult to see any benefit to Aboriginal clients flowing from the loading. However, other Aboriginal health services were unaware of this scheme. Also, we know that a number of chronic disease self-management and coordinated care trials had been running simultaneously with this project, and that some of our participating organisations were involved in both. Services providing health care to Aboriginal clients need to be more aware that by drawing on funds through Medicare for new enhanced primary care items, savings can support primary health care workers to assist clients to manage their chronic conditions effectively, including mental health problems.

Another initiative that came to light during this project was a major scheme to provide up-to-date communication systems and infrastructure to remote services, which would enable access to specialists for consultation and diagnosis, greatly benefiting patients and workers. The potential for on-line workforce and community health education resources through this new technology is yet to be explored.

Some members of the Port Augusta steering committee wanted to know more about the Patient Assisted Transport (PAT) Scheme for rural/remote patients. The research team facilitated this, enabling a better understanding of the scheme, its eligibility criteria and how it could assist Aboriginal clients.

We have discussed all these schemes with the Aboriginal Health Council of SA, who will inform member organisations. Concern was expressed that

some Aboriginal health services do not have the capacity to apply for these funds, and so the Aboriginal Health Council of SA will lobby the SA Department of Human Services to collate such information and facilitate understanding and access to these disparate schemes.

## **Bringing services, community groups and individuals together**

From the beginning, the research team undertook proper consultation (often very time consuming) and ongoing relationship building with the Aboriginal community controlled health services, our partners in the regions. The researchers also worked with a mix of Aboriginal and non-Aboriginal health, welfare, pharmacy, medical, police and other community personnel who were members of the local steering committees. These relationships provided the essential foundation not just for the project but for any future interventions that would be required. While difficult to measure in the research sense, a major initiative throughout the project has been this bringing together of various groups, service providers and community members. This has offered the 'platform' to meet face-to-face (often for the first time) to discuss, share ideas and jointly problem-solve the key issues of concern regarding Aboriginal health, mental health, drug and alcohol use, and medication use. This strategy has proved to be invaluable in that many of these groups have told us that they have gained new insights into diverse and urgent matters related to Aboriginal mental health and safe medication use.

Many of the strategies outlined above involved forging new partnerships to address problems. Other examples brought about as a result of this project include:

- PLAHS and the coordinator of the local Carers Association are now jointly addressing issues for Aboriginal carers, particularly their need for respite and having their own carers' group.
- The chief investigator was consulted on content and strategic directions of PLAHS Alcohol and Other Drug Use Plan.
- PLAHS and the local community mental health team have worked together in joint staff development programs on Aboriginal mental health and drug and alcohol comorbidity, and safe medication use issues.
- Maitland Elders Group and Yorke Peninsula Division of General Practice, who had not met previously, are discussing the concerns and needs of local Aboriginal Elders and their families.
- Muna Paiendi Aboriginal Health Service in Northern Metropolitan Adelaide and the Board of Management of the Lyell McEwin Hospital are developing memoranda of understanding on providing culturally safe services to Aboriginal clients and their families.
- Management of Northern Correctional Services requested discussions

with Muna Paiendi to prevent the cycle of re-imprisonment experienced by Aboriginal people with a diagnosed mental health disorder as a result of being on a treatment order as a condition of their parole, but not attending the mental health team at the hospital for their compulsory medication administration. A memorandum of understanding is being developed by which Muna Paiendi will facilitate the mental health worker attending to the client in their home, or transporting and supporting the client in attending the mental health service.

The willingness of our existing partners to continue to work with us, and the growing number of additional Aboriginal groups seeking information and services from this team, is a major outcome. We believe that this has mainly occurred through 'word of mouth' identifying us as researchers/health professionals/educators who are viewed as reliable, respectful and responsive. There have been approaches from a growing number of Aboriginal groups including community controlled organisations, women's groups, family violence workers, Elders groups, other health workers and service providers from rural/remote and metropolitan areas for this team to assist them with drug and alcohol, mental health and safe medication related issues. They are requesting education and training for workers, help in accessing and dealing with mainstream services, help in addressing the burdens of comorbidities (physical illnesses, mental health disorders, and social and emotional problems) on clients and families, assisting carers and other family members to access culturally appropriate respite and other services, accessing other project monies and resources, and help in applying safe medication management systems.

As a result of our work with the Elders and Women's groups, further collaborative research projects have already emerged. For example, one project is in response to concerns expressed to us by Aboriginal Elder grandmothers about their diminishing opportunities, due to stress, illness and premature death, to pass on their collective wisdom and experiences to future generations in regard to effectively addressing alcohol-related domestic violence. The project has recently received funds from Flinders Institute for Health Research, and preliminary conversations have begun between the research team and Elder grandmothers from the Murray region, Adelaide and the Port Augusta Womens' Group. Two other projects recently funded by Flinders University have received ethics approval and are now underway. These, too, are in direct response to issues identified in the data and through conversations between the chief investigator and rural/remote and metropolitan women's groups. They are a literature review of clinical management of Aboriginal people with comorbidity associated with heavy drinking and diabetes, and a review of literature and hospital separation data regarding pregnant women with a diagnosis of drug or alcohol disorder, and who are identified as from Aboriginal and other cultural/ethnic groups.

## **Promoting successful models of care**

Newly developing relationships are forming with Warriparinga Kurna Healing Centre in Southern Metropolitan Adelaide, Elders from Point Pearce and Maitland in rural SA, and the Aboriginal Sobriety Group (ASG) and Mobile Assistance Patrol (MAP) services in Adelaide. Leaders from UK Health, who recently visited Adelaide, were introduced to ASG-MAP services by the research team and are now considering the ASG-MAP model for disadvantaged people in their regions. The CEO of ASG has accepted an invitation to visit and conduct an education tour on ASG-MAP services and key matters affecting severely disadvantaged Aboriginal people in South Australia.

## **Working across the state together**

### ***Aboriginal Health Council of SA (AHCSA)***

Negotiations flowing on from this project indicate that future courses will be run in collaboration with AHCSA and Flinders University, and these will have clear pathways for career development of workers through articulation with the alcohol and other drugs and mental health streams of Certificate 3, Certificate 4 and Diploma programs in the VET/TAFE sector, and the Flinders University Graduate Certificate in Health - Alcohol and Other Drug Studies. This can also offer realistic pathways into further postgraduate studies such as public health, remote health practice and mental health for eligible applicants. Members of the research team and AHCSA have already agreed to progress the following matters:

- Safe medication management training for health and other community workers in metropolitan rural and remote SA to be provided in September 2003.
- Inclusion of mental health and safe medication management in programming training courses by AHCSA as a newly accredited 'Recognised Training Authority' in SA.
- Enhancing existing strategies to support Aboriginal hospital liaison staff such as gaining funds to support their access to education through AHCSA.
- A joint funding proposal will be submitted to the Commonwealth rural/remote worker support program for funds to support Aboriginal health workers to be released from workplaces to attend training and gain clinical experience in other Aboriginal health services, mental health services, and drug and alcohol services etc.

Other plans include gaining funds to produce relevant, culturally and linguistically appropriate, and user-friendly education resources on Aboriginal mental health and safe medication management issues. AHCSA will undertake a review of suitable models of other health literature and educational resources currently available for clients, carers/family members,

community members and staff (e.g. petrol sniffing, diabetes, asthma, healthy eyes and ears), many of which have also been developed by colleagues from Flinders University, Aboriginal Drug and Alcohol Council and Nunkuwarrin Yunti in SA. Criteria will be set by the AHCSA for assessment of the suitability of such resources as community education models for mental health and safe medication management. These will consider: literacy levels; visual relevance and cultural acceptability; the use of local Indigenous languages; Aboriginal artists' involvement; and target audiences such as health workers, men, women, youth and Elders. Examples may be flip charts, posters, and audio and video productions. Funds will be sought to produce and disseminate these community education resources.

Discussions will be held on the issue of isolation of Aboriginal Liaison officers placed in major general and mental health facilities, and ways to consolidate an effective system of mentorship, information sharing, and access to training and other professional development activities. This aims to ensure that these workers are no longer isolated in undertaking their multifaceted and very demanding role that includes advocacy, cultural interpretation, linking families and clients, counselling, staff development, educating non-Aboriginal clinicians, responding to difficult issues, assisting front line receptionists and clerical staff, referral and after care planning. There will also be consideration of how to effect national standards that include mental health, substance use and safe medication as 'core' aspects of all health curricula, rather than being designated solely as electives or specialty courses. Currently the National Aboriginal Community Controlled Health Organisation (NACCHO) is trying to develop national standards for health curriculum to be used by all registered training providers for Aboriginal health workers, including substance misuse workers and mental health and community workers.

## **Summary**

The project's stages have been completed and its aims have been achieved. Deficits in our previous knowledge about Aboriginal mental health and medication use have been uncovered and many serious issues impacting on Aboriginal mental health and safe medication use have been revealed. We can now more confidently inform Aboriginal people, councils, governments, policy makers, service providers and workers on the seriousness and urgency of the issues impacting on individuals and families, all of which must be addressed if Aboriginal people are to experience improvements in their mental health, social and emotional wellbeing, and decisions, knowledge and safety regarding their use and management of medicines. We have achieved this through effective communication, staying away when appropriate, paying attention to people's needs and concerns, ensuring the application of ethical research practices, and working with Aboriginal partners at their pace, based on their needs and priorities.

A number of interventions have been implemented, including workforce and community education, strategies for safer management of medications, coordinated service delivery, advocacy and Aboriginal capacity building. Evaluations to date have been encouraging, with workers reporting better knowledge and improvements to work practices. It takes time for these types of interventions to have an effect on health status, and hence we have not attempted to measure health outcomes.

Real collaboration between disparate research and community partners relies on Aboriginal service providers and their communities knowing that the researchers are committed to continue working with them beyond the project, if needed and as needed. Effective relationships could not have been developed and maintained, and could not continue beyond this project, had we not been diligent in the attention we paid to trust and building our relationships. A major outcome that is difficult to measure has been the development and ongoing nature of bringing disparate groups together, and building collaborative relationships between the research team members and the various participating Aboriginal and non-Aboriginal services and community groups involved.

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# Chapter 9

## Discussion

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**This chapter was prepared by:**

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### Introduction

This chapter brings together the major findings from each part of the project and considers them together in light of interventions achieved thus far. It is written against a complex backdrop of Australian Indigenous history and culture. As the project progressed, our topic - medication management among Aboriginal people with mental health problems - led us deeper and deeper into Indigenous issues and understandings. Throughout the project, we found medication management could not be isolated from a diverse range of wider contexts, issues and considerations. This was not entirely unexpected on account of findings and experiences from previous research, however we were struck by the depth and strength of cultural, social and historical influences on seemingly all aspects of mental health and medication management. The research design catered well for this. Our project embraced holistic and multi faceted perspectives from the outset, in keeping with an Indigenous perspective on social and emotional wellbeing.

Outcomes of the research were informed by multiple, triangulated data sources:

- literature on Indigenous health, Indigenous mental health, and Indigenous medication management in the Australian national context (Chapter 4);
- interviews on the wider issues impinging on medication management among South Australian Aboriginal people with mental health problems, their carers/families and their health and social service providers (Chapter 5 and Attachments 1-7);
- survey findings from service providers on their roles and health service issues relating to medication management among Aboriginal people with mental health problems in South Australia (Chapter 6); and
- a review of South Australian hospital separation statistics for Aboriginal clients with diagnosed mental health disorders, 1995-2000 (Chapter 7).

As the project progressed and data arising from these various sources were analysed, the subsequent findings were creatively addressed as far as the scope of the project allowed, in keeping with the cyclic nature of action research (Chapter 8). Therefore, this discussion is a reflection on not only

the immediate outcomes of the entire research project and its several parts, but on how it was possible to achieve positive, practical change within the project's timeframe (Chapter 8). Very importantly, we strove to avoid the common pitfall of much Indigenous research - arriving at a set of recommendations without making any difference to the lives of Aboriginal people. We managed to fulfil the ideals of the *Partnership model for ethical Indigenous research* (described in Chapter 3) in pleasingly diverse and substantial ways, considering the magnitude of the problem.

While we applaud the ongoing commitment of Australian government and non-government resources to improving Indigenous health, our findings point strongly to a need for vigorous reassessment of where and how funds are allocated in order to improve all aspects of medication management in relation to the social and emotional wellbeing of Indigenous peoples (see recommendations, Chapter 10). The discussion is related to recently published performance indicators for monitoring the effect of Australia's National Strategy for Quality Use of Medicines [1].

## **Major findings from multiple data sources**

### **Literature on Indigenous health, Indigenous mental health and Indigenous medication management in the Australian national context**

This literature/document review is presented in Chapter 4. Literature accessed for this research project served both to locate the research within its broader context and as a source of data. In overall terms (and in the main over the past five years) we found abundant literature on Australian Indigenous health in general, some literature on Australian Indigenous mental health, and very little on medication management among Indigenous Australians. Considering the literature on Indigenous mental health and medications together, an obvious gap presented. Medication management among Aboriginal people with mental health problems clearly was an under researched area deserving attention.

Increasing focus on the poor health of Aboriginal Australians was apparent in the literature. This has been accompanied over the decades by calls from Aboriginal and non-Aboriginal authors to understand the situation from historical and cultural perspectives and to act in accordingly sensitive ways. Government and non-government interventions (often funded research projects) designed to improve the health of Aboriginal Australians have also increased over the years, and been implemented increasingly by Aboriginal leaders and health professionals. A major national development was the comprehensive health strategy laid out by the National Aboriginal and Torres Strait Islander Health Council, involving the set up of numerous

Aboriginal-controlled health services [2]. At the same time, state initiatives such as *The first step ... The South Australian Aboriginal Health Partnership* [3] were occurring throughout the country.

Some major mental health developments for all Australians such as the *National Mental Health Strategy* [4] and *Burdekin Report* [5] acknowledged the particular needs and issues impacting on Aboriginal mental health. Conceptualising mental illness among Aboriginal people as a comprehensive and embracing notion related to social and emotional wellbeing was an important breakthrough. Health professionals or Aboriginal health service providers were no longer limited to traditional psychiatric diagnoses and treatments. Instead they could take a more useful, holistic perspective that included all aspects of an Aboriginal person's life and circumstances, including family, history, social, economic and emotional factors affecting both physical and mental health status and wellbeing.

The *Ways Forward* report on Aboriginal mental health [6] and *Bringing them Home* report [7] were enormously influential in highlighting the need for specialist social and emotional wellbeing services for Aboriginal people. Subsequently, Aboriginal people were identified as a priority group in the *National Action Plan for Prevention and Early Intervention for Mental Health* [8]. Recommendations within this Action Plan informed our research project, particularly in terms of understanding Aboriginal mental health within a context of whole community wellbeing and historical events, increased culturally appropriate initiatives, joint planning between Aboriginal and mainstream organisations, and increased training of Aboriginal people as practitioners in Aboriginal health and education settings.

Countering this raft of initiatives to improve Aboriginal mental health reported in the literature were the latest, very sobering national statistics on the health and welfare of Indigenous Australians [9, 10]. Based on expectations for all-Australian rates, there were markedly more deaths from mental health disorders, more suicides, more hospital separations for mental disorders including alcohol/drug diagnoses and assault, and proportionally more incarcerations among Aboriginal people than among non-Aboriginal people.

In so far as the literature was concerned, we thus entered (as researchers on this project) a highly complex and bemusing arena lacking any comprehensive reports about medication management among Aboriginal people with mental health problems. Now, at the point of discussion of findings from the project, we are able to substantially fill this void. The project has generated knowledge about aspects of medication management among Aboriginal people with mental health problems, including alcohol/drug problems that were hitherto neglected, unknown and generally unsuspected, and certainly unreported.

## **Interviews on the wider issues impinging on medication management among South Australian Aboriginal people with mental health problems, their carers/families and their health and social service providers**

This component of the research is summarised in Chapter 5. Detailed reports of this qualitative research in the regions are in Attachments 1-7, and some have also been published as stand-alone reports [11-13]. Altogether, over 130 persons (Aboriginal clients, carers and family members, and Aboriginal and non-Aboriginal service providers) participated in 58 individual or group interviews, conducted in a range of urban, rural and remote regions of South Australia. The interviews explored experiences, contexts and issues surrounding medication management for Aboriginal people with mental health problems, service provision pathways, and availability and usefulness of information and advice about medication management and related issues.

Although semi-structured interviews were conducted within the parameters of a specified interview schedule, there was a wide range of findings. In virtually all respects, medication management was embedded within contexts and issues of wider and greater importance to all interviewees, making it necessary for us to similarly conceive and present the findings. It deeply concerns us that findings were overwhelmingly negative and related to nine recognisable problems:

1. Social and emotional wellbeing issues for all Aboriginal people.
2. Stressors on Aboriginal health services and providers.
3. Lack of adequate training for the Aboriginal health workforce on safe medication management and mental health/alcohol and drug issues.
4. Inadequacies of mainstream health services for Aboriginal people.
5. Unwitting erosion of trust and confidentiality within Aboriginal health services.
6. Low English language literacy and numeracy skills of some Aboriginal clients.
7. Inadequate and remote living arrangements for many Aboriginal people.
8. Problems with alcohol use.
9. Institutionalised and individual racism in the community at large.

Each of these problems impacted in major, negative ways on safe and effective medication management, including:

- all aspects of medicines (including obtaining, administering and storing) assuming a low priority in relation to other social and emotional wellbeing issues, especially relating to family deaths and wider community, consequences of poor physical and mental health, and

- widespread unemployment and poverty in the community;
- reduced efficiency of delivery and administration of medications by health workers and others due to work overload and complex working arrangements in Aboriginal health services burdened by bureaucratic constraints and confusions;
  - reduced ability of health workers and others to practice safely and effectively, and provide appropriate advice and assistance to clients, due to shortfalls in workforce education in medication management, mental health, drugs and alcohol, and cultural safety;
  - medications being unavailable or available too late and after the event because of mainstream health services not operating at the times of Aboriginal people's greatest need, or appointment times and arrangements not accommodating the unpredictability and physical remoteness of Aboriginal lifestyles and housing;
  - confidential medication issues being overlooked or mismanaged due to the difficulty Aboriginal health services have in providing a confidential service within their own community when the workers are themselves members of that community and possibly involved in the same issues as their clients;
  - medication instructions (including dosage, frequency, side effects and repeat prescription requirements) being misunderstood or ignored because of low literacy skills among many Aboriginal people, especially Elders;
  - medications not reaching their point of delivery to Aboriginal clients due to inadequate dispensing arrangements, lack of local transport, or being delivered, administered or stored in unhygienic, unsafe or inappropriate ways due to the remote and inadequate living arrangements of many Aboriginal people;
  - mal-absorption and non-absorption of medicines due to associated alcohol intake or non-compliance with medication instructions due to physical or mental incapacity due to associated alcohol intake, or misuse of medicines such as swapping or trading while under the influence of alcohol - all potentially life threatening to the individual directly affected by alcohol as well as those in the immediate vicinity, such as family members, due to violence associated with the alcohol intake;
  - diminished interest and motivation in relation to all aspects of medicines (in conjunction with diminished interest and motivation in relation to health management in general) associated with reports by Aboriginal people of receiving less adequate health attention than non-Aboriginal people and generally, in all aspects of their lives, being treated as less worthy and less capable than non-Aboriginal people.

A significant finding from the interviews was that *all* Aboriginal people and their families suffer (in so far as the data from this project indicate) a degree of social and emotional distress to a greater or lesser extent. This finding has enormous implications, as outcomes can reasonably be regarded as applicable to *all* Aboriginal people who need to take medication.

## **Survey findings from service providers on health service issues relating to medication management among Aboriginal people with mental health problems in South Australia**

This component of the research is described in Chapter 6 and has also been published separately [14]. Respondents to this purposive survey comprised 114 health and other human service providers, including: Aboriginal health workers; nurses; mental health workers; substance misuse workers; managers; liaison officers; social workers; police; pharmacists; general practitioners; community workers; counsellors; paramedics; educators; 'bringing them home'; and family support workers. They worked principally in organisations within the health, community/social services and police/correction sectors, and were in frequent contact with Aboriginal clients.

We were very concerned to find one third of respondents had received no training in mental health or alcohol and other drugs (nearly all police/corrections workers received some training while many health and community/social sector workers were untrained). Interestingly, while self-reported understanding of medicines and illicit drugs was adequate/good, there was no association with the training received. Seventy per cent of respondents reported having a poor understanding of traditional Aboriginal medicines.

In terms of quality use of medicines, about half of all respondents reported some training as part of a professional qualification or in-service training (particularly registered nurses and pharmacists). While only about one third of respondents reported ever giving or managing clients' medications, these were, disturbingly, not necessarily those who had received training. These individuals believed training would be relevant but cited access, availability, cost, suitability and time as inhibiting factors. Others who stated that handling medications was not part of their job still wanted to be informed so they could better assist their Aboriginal clients. Education needs were clearly evident and influenced events within the project as discussed below.

Numerous health service issues were identified as impacting on Aboriginal people with mental health problems, deepening our growing concern at the complexity and gravity of circumstances surrounding medication management. These included: money problems; racial discrimination; poor availability of traditional health care and mental health services (urban and rural/remote areas); poor transport; unavailability of local specialist services; and reticence to use services due to perceived or actual non-confidentiality and racism. Respondents commented that Aboriginal people were coping with multiple and complex issues in their lives, and therefore matters of health and medicines did not necessarily take priority.

Many medication issues impacted on Aboriginal people with mental health problems. Drug and alcohol misuse was the biggest issue for people from both urban and rural and remote areas. This was followed closely by cost, ability to comply with prescribed medication regimes, feelings about the likely usefulness of medications, sharing of medicines and side effects (urban areas), and poor levels of information/knowledge about medication (rural and remote areas). Itinerant people, and those with major mental health problems, had particular difficulty accessing and managing their medications. Some respondents believed that medication compliance was enhanced if medication was dispensed in Webster packs or dosettes.

Provision of information to Aboriginal people about mental health and medications was a priority for service providers, and different avenues were utilised, including various written, verbal and visual forms. Nevertheless, they considered there is much scope for improving information and communication at individual and community levels through more culturally appropriate means, including the use of local languages, graphics, workshops, story telling, radio, television and positive role models.

### **Review of South Australian hospital separation statistics for Aboriginal clients with mental health problems, 1995-2000**

This novel review (Chapter 6) revealed important information not previously accessible. By way of careful negotiation and ethical clearance with appropriate bodies, it was possible to identify detailed hospital morbidity data for South Australian Aboriginal people with diagnosed mental health problems. A special feature of the review was that it included Aboriginal people with both principal and additional diagnoses, whereas most reviews focus on principal diagnoses only and do not take account of the complexity of comorbidities.

Findings of the review show an increased number of hospital separations over time for Aboriginal people with mental health disorders. Four out of five of these also had dependent or non-dependent alcohol and/or drug problems. Further, most patients also experienced other complex health problems such as diabetes, and renal and heart disease. The review also highlighted a worrying association between mental health problems and preventable injury: approximately 25% of Aboriginal hospital separations with mental health diagnoses also had diagnoses of injury, poisoning or other consequence of external causes such as assault, falls or crashes. We believe it is the first time such an association has been documented. It is noteworthy that 'adverse effects of drugs' (i.e. pharmaceuticals) attracted little attention as an external cause of injury, in keeping with the paucity of available information about medication management.

The review revealed disturbing new information about the rate and nature of comorbidities among Aboriginal people. Considering the data pertained to hospital separations only, it can reasonably be assumed from our other data sets that the comorbidity rate is even higher among Aboriginal people because many do not seek medical treatment or hospitalisation. Comorbidity is thus the norm rather than the exception, giving further cause for concern in terms of the complexity of medication management. The implications of this information for medical, psychological and allied health care are profound.

## **Recognising a serious problem**

Drawing all findings from the entire project together, a hitherto unrecognised picture emerges of medication management of Aboriginal people with mental health problems. Accepting the wider interpretation of mental health as social and emotional wellbeing, we recognise all Aboriginal people suffer a degree of social and emotional stress and that this profoundly diminishes their quality use of medicines, largely because health and medications are subsumed by more pressing issues, and effectively coordinated local services are virtually inaccessible. This diminished compliance and effectiveness is severely compounded by the realisation that comorbidity is the norm among Aboriginal people. They do not suffer just one medical or mental condition but most probably a combination of at least two and usually more. Diabetes, renal disease, heart disease and many other serious medical conditions are likely to be combined with each other, as well as with mental problems ranging from major psychiatric disorders to a wide range of social and emotional problems including injury resulting from alcohol misuse and violence. The gravity of the picture is appreciated when one considers that each condition reasonably requires a medication regime that is either not implemented at all because comorbidity has not been detected, or has only been partially implemented due to a wide range of client non-compliance factors and deficiencies in service providers' education, and lack of clinical guidelines and protocols for co-management of comorbidities.

## **Towards a positive future**

In keeping with the ideals of our particular research model (Chapter 3), and noting Hunter's advice not to 'recoil' from the enormity of change needed, or to get 'trapped in the doldrums' [15], rigorous and sustained efforts were made throughout the project to turn around the negative findings as they were identified at the local level. While obviously unable to resolve the serious medication management problems revealed by the entire project, we nevertheless were able to initiate some substantial interventions (Chapter 8) in relation to:

- 1.. Workforce and community education
  - local workshops for workers and community leaders



- health information for community members and workers
  - professional education programs
  - international conference
  - future planning for education
2. Improving access to, and safe management of medications
    - access to essential medications
    - safe medication transport
  3. Coordination of care for Aboriginal people with mental health problems
    - inclusion of mental health and safe medications use in regional health plans
    - developing a model for coordinated Aboriginal mental health care and safe medication use in rural/remote South Australia
    - other coordinated care initiatives
  4. Advocating for, and supporting ways to increase capacity of Aboriginal service providers and communities
    - informing services of government initiatives relevant to Aboriginal mental health and safe medication use
    - bringing services, community groups and individuals together
    - promoting successful models of care
    - working across the state together

Evaluations of these strategic interventions were positive and in many cases the interventions are either ongoing or have provided an impetus for other related activities. Particularly pleasing is the self-reported uplifting effect they have had on the morale, confidence and knowledge of those involved, especially Aboriginal clients, health workers and carers. We believe the entire project, despite the gravity of the problems it has revealed, has achieved a degree of empowerment for those who needed it most - Aboriginal people and those who serve them. We remain deeply concerned and dismayed at the racism experienced across all regions, as reported by the various Aboriginal people we have connected with during this research, and believe real progress with safe medication management (or indeed all aspects of social and emotional wellbeing and general health) will not be achieved until this is eliminated at individual, institutional and wider levels in the Australian community.

In closing this chapter, we note that this project and its findings are congruent with the *Quality Use of Medicines Strategic Action Plan* [16] and *Indicators* [1]. For example, elements of two of the six key building blocks for supporting the quality use of medicines (education and training, and provision of services and appropriate interventions), and the associated process indicator of 'Commenced preliminary development work including needs assessment' [1](p. 6) can be identified within this project.

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# Chapter 10

## Recommendations

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### Introduction

In this research we used a participatory action approach to explore and address issues impacting on safe use of medications by Aboriginal people with mental health problems, their carers and other family members. Multiple methods for collecting and interpreting data were used (chapter 3), and the findings are described elsewhere in this report (chapters 4-9 and attachments 1-8) [1-4].

The findings affirm that social distress and adverse living conditions experienced by most Aboriginal people are the legacy of past and ongoing racist policies and practices. The research highlights that many Aboriginal individuals and communities live in extreme poverty, with poor housing, limited education and employment opportunities, inadequate public infrastructure, and poor access to health and other services, all of which strongly influence the level of access to, usage and safe management of medicines. It is evident that social and emotional wellbeing problems are widespread among Aboriginal people, and that multiple coexisting physical acute and chronic health problems are the norm, which has further implications for safe medication use and management. Mental health disorders are often associated with problem use of alcohol and other drugs, which also adversely affects safe medication use.

### Method

The research team and the Statewide steering committee (chapter 3) discussed the issues revealed by the qualitative and quantitative data, and collaboratively developed the recommendations. These recommendations were also informed by the local strategies and recommendations developed as part of this project in the different SA regions in which the research was conducted (attachments 1-8). It is clear that many of the underlying issues (racism, social disadvantage, incremental grief and loss) are fundamental threats to Aboriginal well being, and will only be addressed through sustained commitment of resources and energy, and culturally respectful and accessible services. However there are a number of key issues relevant to medication management for Aboriginal mental health which could be solved through creative redirection of resources/personnel, modifications to policy and practice, collaboration, better coordination and integration of services, targeted education and training, and lobbying for, and accessing, additional funds for sustainable programs rather than short term or 'once off' pilot projects [5, 6].

## Recommendations

The recommendations are consistent with the national Quality Use of Medicines strategies, across government policy initiatives, and proposed reforms of the SA health system [7, 8]. Despite numerous reports and plans, including clear guidelines to achieve seamless quality use of medication in hospital and community settings [9], Aboriginal people with mental health problems still experience serious shortfalls in access to quality support for safe medication management, putting their health at risk. Carers and other family members of Aboriginal people with mental health problems are also missing out on appropriate support, further compromising their health and wellbeing, and contravening government endorsed action plans, eg to safeguard the human rights of children [10].

## Services

1. Ensure that all Aboriginal people in SA have ready access to affordable and culturally respectful health, medication and related services.
2. Ensure that all Aboriginal clients have equitable access to subsidies and other supports for their health care and essential medication use wherever they access the health care system.
3. Facilitate access to bona fide traditional healing practitioners and medicines.
4. Organise all health services so that hospital and community pharmacists, registered nurses, medical officers and Aboriginal health workers collectively and separately ensure that all Aboriginal clients and their carers/families receive sufficient time, understandable information and education to make informed decisions about their medication regimes and how to safely manage their medications, at every episode of care.
5. Implement procedures and systems in all services that provide medicines to Aboriginal clients at home/in camps for timely transport, provision, storage and supervision of safe medication use.
6. Actively target Aboriginal and mainstream health services with information about funding opportunities for additional staff, resources and other supports.

## Coordination of care

7. Ensure that provision of care is coordinated within and across all health-related systems (ie health, mental health, drug and alcohol, social support and criminal justice systems; mainstream and Aboriginal services; local, regional and metropolitan services; and government and non-government organisations)
8. Integrate mental and general health care for Aboriginal clients and their families at local, regional, rural/remote and metropolitan services.
9. Ensure timely and effective communication between specialist service

providers and referring GPs, Aboriginal health services and other primary care providers to ensure continuity of care for Aboriginal people with mental health problems.

10. Implement effective communication systems between key services eg through clearly identified and agreed pathways and protocols of care, memoranda of understanding, joint funding submissions, service agreements, reporting and staff appraisal systems.
11. Encourage uptake of targeted funding schemes to employ well trained and supported Aboriginal health personnel to coordinate and support safe medication management among Aboriginal clients of GPs and Aboriginal health services at the local level.
12. Advocate for and support Aboriginal carers/family members to enable them to accompany and stay with Aboriginal clients when transferred for psychiatric care and other relevant services.
13. Promote the provision of local services rather than centralised services (eg GPs, local mental health and drug and alcohol services, Aboriginal services) to care for Aboriginal clients with mental health and substance use problems, in partnership with carers/family members.
14. Conduct research to evaluate and refine integrated Aboriginal mental health care and medication management systems to inform best practice for local needs and contexts.
15. Provide well-supported and coordinated pathways of care for Aboriginal juvenile and adult offenders with a mental health disorder, and their families, when entering or exiting a correctional facility, and/or on parole, regarding their safe medication management and ongoing mental and general health care.

## **Carers and other family members**

16. Provide for community education activities on the rights and special needs of Aboriginal carers and other family members, and how to access respite services and ongoing resources.
17. Provide effective support mechanisms for Aboriginal carers/family members.
18. Fund and support Aboriginal carer groups in local communities.
19. Promote the provision of locally available services for carers and other family members of Aboriginal people with mental health and substance use problems.

## **Workforce development and education**

20. Provide adequate induction, ongoing training, clear policies, protocols and reporting procedures for safe medication management to all personnel with any role in handling, transporting, storing, providing or assisting in the administration of medications.

21. Provide basic and specialised training for all staff of Aboriginal and mainstream health and related services in mental health, social and emotional wellbeing, drug and alcohol, and cultural safety.
22. Ensure that this training is provided locally, meets the needs of local services and communities, is regularly updated, and articulates with further education pathways.
23. Ensure that safe medication management, mental health and drug and alcohol are included and assessed in core curricula of all relevant Vocational Education and Training (VET) and tertiary education programs, and strive for a nationally consistent approach.
24. Foster and resource networks of workers to ensure information flow, peer support, and sharing of knowledge and skills regarding safe medication management, care of Aboriginal people and families with mental illness and other health problems, and related issues.
25. Build the capacity of the Aboriginal workforce to deliver better health and social services to their community members through improved access to education and employment initiatives.
26. Ensure that all workers, including drivers, of Aboriginal health, substance misuse, mobile assistance and social and emotional well-being programs have a strong network of mentors and peer supports, and safe workplaces, that actively promote mental health and well-being of all employees.

## **Community development**

27. Support Aboriginal communities in their right to self-determination of their own health, including mental health, outcomes and goals.
28. Provide culturally and linguistically appropriate community education and health promotion programs and resources about Aboriginal social and emotional wellbeing, mental health issues, drug and alcohol issues, and safe use of medications, to reduce the shame and ensure that all communities have access to relevant and understandable information and resources.
29. Continue to implement and enhance proactive Aboriginal employment schemes in the wider community, private and public enterprise, to enhance career opportunities and leadership roles, reduce poverty and raise morale.
30. Ensure that all members of Aboriginal communities are well informed about their moral and legal rights to non-racist mental health, drug and alcohol and general health and social services.
31. Ensure that members of all Aboriginal communities understand, have support and can easily access legal and other mechanisms, eg the Equal Opportunity Commission, to report and lodge complaints of racism of any service providers.

32. Ensure that members of all Aboriginal communities understand, have support and can easily access the SA Guardianship Board and Public Advocate regarding their own or family members' mental health issues and related needs.

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# Attachment 1

## Report on research conducted in the Port Augusta Region

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### **This report was prepared by:**

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- Charlotte de Crespigny
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### **Also involved in this project were:**

- Anita De Bellis, Mike Turner and Sharon Cruse from Flinders University
- Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council Inc. (SA)
- Port Augusta Steering Committee comprising staff of Pika Wiya Aboriginal Health Service and other local health services and community organisations.

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## **Introduction**

Past and ongoing racist policies and practices have resulted in profound and prolonged grief, disempowerment and social disadvantage for Aboriginal Australians. This has led to widespread social and emotional wellbeing problems, and multiple physical, spiritual and mental health disorders[1-6]. The ongoing burden of living with such complex health problems, or caring for someone with these problems, places inordinate strain on the physical and mental health and wellbeing of individuals and the coping capacity of the Aboriginal community as a whole. Sadly, despite numerous enquiries, reports, recommendations and strategic plans[7-11], Aboriginal Australians are still the sickest and poorest in the nation [3, 12].

Of particular concern is the unrelentingly high prevalence of mental health problems among Aboriginal people. Recent national statistics [3] indicate that compared to non-Indigenous Australians, Aboriginal people are hospitalised more often for mental or behavioural disorders and are twice as likely to die from a mental disorder. Furthermore Aboriginal people have disproportionately high rates of assault, suicide and incarceration. It should be remembered that from an Indigenous perspective mental health is a socially constructed concept that incorporates the spiritual, social, cultural, and physical dimensions of life, and are intertwined with adverse economic and political conditions [13]. Consequently, to be influential, reports and plans relevant to Aboriginal mental health must prioritise wellness and promote holistic culturally informed approaches to healing [5, 10, 14-17]. However current regional mental health plans may not yet adequately address these critical Aboriginal-specific issues [16, 18, 19]. For example, a recent seminar on social and emotional wellbeing issues in Port Augusta and the Far North of South Australia, while acknowledging and celebrating the efforts of local and state health and welfare organisations, clearly highlighted the ongoing and urgent need for better understanding of Aboriginal culture and experience, more accessible and appropriate local services, mechanisms to enable family and community support for people in distress and their carers, better communication at all levels, and adequate resources to implement and sustain these initiatives [16]. In Port Augusta, Pika Wiya Aboriginal Health Service is addressing many of these concerns, and has made considerable progress, but is limited by financial and human resource constraints [5, 10, 14-17].

Safe and effective medication use by people with mental health problems and their carers is a major issue, particularly if there are coexisting health problems. Social, health and economic issues associated with the use of medications include intoxication, excessive use and dependence, adverse drug reactions, side effects, drug interactions, hospital admissions, accidents and falls, re-incarceration, misdiagnosis or exacerbation of dementia and other conditions, and psychological effects of polypharmacy [20-22]. The combination of prescribed medications, together with other substance use, eg over the counter medicines, illicit drugs or alcohol, can compound the physiological, psychological and social problems of mentally ill persons [23]. National policies and strategies for the quality use of medicines have been formulated [24, 25] in consultation with consumers [26], professionals, government and industry. The Commonwealth also funds a range of programs to improve quality use of medications through the Quality Use of Medicines Evaluation Program [27].

There is little research on medication use specific to Aboriginal cultures, apart from earlier studies from this research team [20, 28] which show that medication management for Aboriginal persons and their carers is problematic because of cultural issues; limited access to quality, culturally appropriate medication information and support; sparse economic resources; lack of education; and differences in understanding, personal resources and skills. Other literature has focused on prescribing rates [29], compliance [30], the importance of good communication [31, 32], workforce development [33], pharmacy services [34] and integration of services [35, 36]. Although it is agreed that substance misuse and polydrug use have major negative impacts on health [37, 38], there is little evidence of sustained improvement in health outcomes resulting from the programs aimed at addressing these issues among Aboriginal people [37]. No research specific to medication management for Aboriginal mental health was identified. The lack of literature highlights the need for research to inform policies, health promotion, education, and practice guidelines for safe, effective medication management for Aboriginal people with mental illness.

### **Recent initiatives at Pika Wiya relevant to medication management**

In 2000 Pika Wiya Aboriginal Health Service initiated a review of its medication services, prompted by the increase in the size and multiple locations of the organisation and the need to bring it in line with current legislation [39, 40]. A pharmacist was employed to review drug room and dispensing practices. As a consequence of the review, Pika Wiya Aboriginal Health Service purchased the services of a pharmacist from Port Augusta hospital, to assess clients' medications and provide information to clients on self-management of their medications.

Pika Wiya Aboriginal Health Service also negotiated with the Port Augusta Hospital pharmacy, local community pharmacists and SACRRH to develop lectures on medication management and related topics for Pika Wiya staff. The lectures were delivered over a 20-week period to Pika Wiya staff, and it is planned to repeat the sessions in future. These lectures were subsequently adapted into CD-Rom format for use in training staff at other Aboriginal health services [39, 40]. Pika Wiya Aboriginal Health Service is also involved in the development of an interactive CD-Rom on medication management for health workers' self-directed learning.

Pika Wiya Aboriginal Health Service chose to become a project partner and site in the "Our health in our hands in our region" SA Shared Health Care initiative funded through the Commonwealth Department of Health and Ageing. This project has given Pika Wiya Health Service the opportunity to find ways to evaluate the holistic health concepts which Aboriginal medical services aim to address.

Pika Wiya has developed an extension to the Flinders University Coordinated Care Training Unit tools for chronic disease self-management and introduced a social care plan [41]. Further to this initiative, health assessments and care planning are to be core components of Pika Wiya Health Service business, and these include a medication management review which will be done by the pharmacist, doctor and health worker.

## **Research design**

In response to the issues outlined above, a team of researchers from the Flinders University School of Nursing and Midwifery and the Aboriginal Drug and Alcohol Council (SA) designed a project entitled "Better medication management for Aboriginal people with mental health disorders, their carers and other family members". Funding was obtained from the Commonwealth Department of Health and Aged Care Quality Use of Medicines Evaluation Program for the 3-year SA-wide project, and from the Australian Rotary Health Research Foundation for a pilot study in metropolitan Adelaide [42].

This SA-wide study, using multiple qualitative and quantitative methods, set out firstly to explore the particular needs, experiences and contexts of Aboriginal people with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications; secondly to develop recommendations based on the findings in collaboration with Aboriginal communities; and thirdly to implement and evaluate selected strategies in certain regions. Mental health disorders included conditions such as depression, dementia, anxiety, schizophrenia, bipolar disorder, substance use disorders, grief and loss, and social and emotional

distress. The project was conducted in different locations in SA, including metropolitan Adelaide, Port Lincoln, Port Augusta, Coober Pedy and Riverland, in consultation with local Aboriginal communities and other stakeholders. Multiple research methods were used to collect and analyse qualitative and quantitative data in each location and for SA as a whole, including thematic analysis of interviews and focus groups with clients, carers and service providers in each region, and review of literature and key documents. Findings from each location were considered separately as well as together. These were augmented by an analysis of ABS hospital separation data of Aboriginal people with a diagnosis of mental health and associated disorders in SA and a statewide purposive survey of over 200 key mainstream, including mental health services and police, and Aboriginal service providers in contact with Aboriginal people with mental health disorders. These data have informed local and statewide recommendations and strategies for improved, culturally appropriate policies and practices for safer medication management by mentally ill Aboriginal Australians, their carers and other family members.

This paper reports only on the component of the project conducted in the Port Augusta area. This report presents the findings from the interviews and focus groups with clients, carers and service providers, and the recommendations that were collaboratively developed in response to the findings.

## **Rationale**

We chose to use multiple methodologies and different locations in order to collect and analyse a range of primary and secondary research evidence, and build up a rich and comprehensive understanding of the issues and contexts around medication use for Aboriginal mental health across SA. Congruence of findings from different areas and/or using different research methods strengthened the validity of findings and affirmed important issues.

The use of semi-structured interviews and focus groups provided a rich understanding of workers' and Aboriginal community members' knowledge, perceptions, experiences and practices in relation to medication management and mental health. Qualitative research does not seek to be representative of populations, or generalisable in the statistical sense, rather it provides depth and detail, highlighting similarities and differences between individual accounts, to complement and strengthen other research methodologies and knowledge.

The research was underpinned by the principles of ethical Indigenous research [42]. The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, and

the Aboriginal Health Council of SA, as well as the Boards of Management of the organisations that hosted the project in each location.

The project empowered and benefited Aboriginal people. The Port Augusta component of the project was conducted in partnership with a major Aboriginal health care provider, Pika Wiya Aboriginal Health Service, the Port Augusta Substance Misuse Service, Kunga Tjutaku Ngura Aboriginal Women's group, and other community members and service providers, and in accordance with community needs and wishes at all times. The needs of the participating individuals and communities were always more important than the project requirements. The project offered employment and training opportunities for Aboriginal people. Outcomes of the project include better understanding, and improved policy and practice in relation to safe medication management for Aboriginal mental health, to benefit the health and wellbeing of Aboriginal people.

## **Aims**

The aims of the SA-wide project were:

1. To explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications.
2. To recommend strategies to improve quality use of medicines by this group, informed by the findings.
3. To implement and evaluate selected recommendations.

Activities in each location varied in extent and duration, depending on the priorities of local Aboriginal communities. The main project activities in Port Augusta related to aims 1 and 2.

## **The Research Project in Port Augusta**

### ***Port Augusta Steering Committee***

The research activities in Port Augusta were planned and conducted by members of the research team in consultation with the Port Augusta steering committee, to ensure that the research was responsive to the needs of local Aboriginal communities, and conducted in a culturally acceptable manner. The Port Augusta steering committee comprised the research team, representatives of Aboriginal groups in the Port Augusta and surrounding areas, and those who provide health and social services to the client group and their families (Appendix 1).

The committee was convened in early 2001 to guide all aspects of the research. The steering committee met formally three times over the next 18 months, and there were also numerous email and telephone contacts. Pika Wiya Aboriginal Health Service Inc hosted the Port Augusta component of this SA-wide project, providing the venue for steering committee meetings, and participating in the steering committee and consultation. Kunga Tjutaku Ngura Aboriginal Women's group and the Port Augusta Substance Misuse Service were also part of the steering committee but were consulted separately.

The steering committee was invited to advise on recruitment of an Aboriginal research assistant acceptable to local Aboriginal communities, engaging potential participants, drafting and piloting the interview guide, follow-up on issues raised by the local Aboriginal research assistant on behalf of anonymous interview participants, and drafting reports and recommendations. The Aboriginal research assistant was specifically trained by this team and received a certificate outlining the training received. We have used a similar approach successfully for previous research on medication use by Aboriginal people with mental health disorders [28], medication use by older Aboriginal women [20], consumer-driven projects [21, 43, 44] and other research [45-47].

### ***Data collection***

Data was collected in early 2002. Rich experiential qualitative data was collected through in-depth interviews and focus groups with consumers and service providers. Potential interview participants included adult Aboriginal people diagnosed with a mental health disorder, or culturally determined social and emotional wellbeing problems including substance misuse, their carers or other adult family members, living in Port Augusta, Copley or Nepabunna. The Aboriginal research assistant, or an acceptable member of the research team, contacted potential participants and invited them to be interviewed for the project. Importantly no names or identifiers were revealed by the Aboriginal research assistant to any member of the research team, the data analyst, or members of the steering committee.

Health and welfare professionals, drug and alcohol workers, an Aboriginal self help community group, and other service providers from Port Augusta and Copley were interviewed also. The inclusion criteria for this group were that they provide professional health services or social support to Aboriginal people diagnosed with, or experiencing, a mental health (social and emotional wellbeing) disorder, including alcohol/drug problems, their carers or other family members. Purposive and opportunistic sampling strategies were used to gain a range of voices and viewpoints.

One-to-one interviews or focus groups with groups of 2-8 people were conducted by an Aboriginal research assistant or another member of the

research team, following a semi-structured interview guide. These conversations were recorded on audiotape or in writing with informed consent of all participants. Participants were assured of confidentiality and anonymity, and could choose not to answer any question and could withdraw their consent at any time. The interviewer made notes (written and/or taped) to supplement the interviews.

Engaging with the communities and negotiating interviews took considerable time, multiple telephone calls, and generally several meetings. A total of 31 clients, carers and workers participated in 11 interviews and focus groups:

- Interview with a carer of young man with a mental health disorder
- Interview with a carer of another young man with a mental health disorder
- Interview with carer of an elderly man with a mental health disorder
- Interview with a coordinator working with Aboriginal families
- Interview with a social worker
- Interview with a women's worker
- Focus group with two Aboriginal health workers
- Focus group with 3 workers from Pika Wiya Aboriginal Health Service
- Focus group with 12 Aboriginal women community members
- Focus group with 3 Aboriginal women
- Focus group with 2 health workers and 3 Aboriginal community members from the Copley area

The Aboriginal women and community members had a range of complex physical illnesses and social and emotional wellbeing issues including substance use problems, and/or cared for people with these problems.

Tapes and handwritten notes were transcribed verbatim. Where possible, the Aboriginal interviewer checked the accuracy of transcripts and assisted with local terminology and language. Consultation also occurred with a member of the research team who was a senior Aboriginal man familiar with local language, terminology and cultural issues.

#### ***Data analysis and development of recommendations***

Preliminary qualitative analysis of each interview and focus group transcript was conducted, based on the headings in the interview guide. The NVivo software package for qualitative data analysis was applied in this process to categorise and manage the data [48]. Key information and quotes from interviews were coded under those headings while reading and re-reading the transcripts and listening to the tapes. These were then categorised further into themes, based on the issues and concepts mentioned in the grant application and interview guide and others that emerged from the interviews. A short summary was then prepared for each transcript. Finally, all the findings were integrated into one document, to give an overall



picture, highlighting common themes, key issues, similarities and differences, taking particular care not to imply overtly or subtly any identifiers that may reveal their identity by area or cultural group, thus preserving anonymity for all participants. The analysis process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and as deeper analysis occurred [49]. Other researchers from the team cross-validated the analysis [50].

Preliminary findings were presented to steering committee members and key informants for further elaboration and validation. Notes from these meetings were included as data where appropriate. The researchers directly involved in the local project recorded their reflections and ideas emanating from interviews with key informants, focus groups and steering committee discussions, and these too were included as data.

Informed by the findings, recommendations for improving quality use of medications were developed collaboratively by the research team, steering committee, Aboriginal health workers and other stakeholders. Where time and resources permitted, selected recommendations were implemented and evaluated as part of this project.

## **Findings**

### **Demographics**

Most of the client/carer participants were Aboriginal community members. Health and community workers who participated were both Aboriginal and non-Aboriginal. All were adults over 18 years of age. With the exception of the Copley/Nepabunna group, all lived in or very near to Port Augusta, although some revealed that they were from or identified with traditional communities in remote areas away from Pt Augusta. Education levels varied widely, from carers who had only attended primary school to health professionals with postgraduate qualifications. The carers' employment history included farm and domestic work. The main income for most of the carers and clients was a government pension of some kind. According to the Pika Wiya Aboriginal health workers, Aboriginal people in the area come from a number of language groups from surrounding districts and further afield.

### **Use of health care and other community services**

#### ***General Health Issues***

None of the client/carer participants had been diagnosed with a major mental health disorder such as schizophrenia or bipolar disorder, but many

had experienced social and emotional distress, psychological trauma such as grief from loss of family, depression, anxiety, and substance misuse problems. They had different, and often multiple, physical chronic illnesses such as hypertension, asthma, diabetes, arthritis, heart disease and kidney disease, and a history of substance misuse problems. According to the carers the people they cared for had very little understanding of their own health and related issues, including the need for medications to ameliorate the disorder, and safe medication use.

### ***General health services***

The majority of client/carer participants used Pika Wiya Health Services for most of their health needs. Pika Wiya Health Service is an incorporated body under the Aboriginal Services Division of the South Australian Department of Human Services. It has an Aboriginal majority board of management and is staffed largely by Aboriginal workers, three GPs, a registered nurse, and a male social and emotional wellbeing coordinator. There are a number of special programs involving visiting health professionals and supported by specifically trained Aboriginal health workers [17]. Participants said that there were no costs to clients associated with using Pika Wiya services, and transport and a range of other help are provided free of charge to Pika Wiya clients. This was confirmed by Pika Wiya [17]. One carer indicated that he had obtained knowledge about Pika Wiya *“on words of mouth, people telling me”* (PA#1).

Participants also mentioned that many Aboriginal people use other health services in the town including GPs in private practice, Port Augusta hospital, visiting medical specialists, the adult mental health service, local Child and Adolescent Mental Health Service (CAMHS), Ranges Youth Centre, Aboriginal Women's Centre, Red Cross, Family and Youth Services (FAYS), Drug and Alcohol Services Council (DASC) and other government and non government social and community services in Port Augusta.

Copley client/carer participants used Copley Clinic, an outreach service of Pika Wiya. The Copley Clinic has limited resources and is staffed by two Aboriginal health workers who monitor clients' health and wellbeing and arrange for mainstream services via Leigh Creek Hospital or Port Augusta hospital, as required. Participants also talked about an outreach clinic at Nepabunna. The steering committee confirmed that Copley and Nepabunna clinics are outreach services of Pika Wiya Health Services Inc [17].

The Pika Wiya focus group members explained their attempts to cater for the needs of their clients after hours:

*“At the moment there is no after hours formal service (at Pika Wiya) and this is needed. The Aboriginal health workers themselves provide the informal (after hours) services for all health issues, including drug and*

*alcohol and mental health, in their own time because they are community members” (PA#8).*

However the steering committee clarified that Pika Wiya does have an on-call program (limited to 4pm to midnight on weekdays and 8.30 am to midnight on weekends) for medical emergencies [17], and that Port Augusta hospital is staffed 24 hours a day. After hours access to general health services was identified as a problem in Nepabunna and Copley also. However, according to Pika Wiya staff people living in these towns can access Leigh Creek hospital after hours.

### ***Mental health services***

Participants, including workers, gave diverging accounts of mental health (social and emotional wellbeing) services available from Pika Wiya, and elsewhere in the region, highlighting the confusion about what services exist, how to access them, who can access them, and their varying roles and relationships. According to its annual report [17] Pika Wiya employs general practitioners and social and emotional wellbeing workers, but has no specialised mental health professionals on staff. Pika Wiya adult clients with mental health disorders are referred to the mainstream adult mental health service in Port Augusta. One participant said that the mainstream mental health service does not share information with Pika Wiya regarding some Aboriginal clients who have mental health disorders (PA#8), making it difficult for Pika Wiya to coordinate care. In contrast, other participants told of strategies to coordinate care and service provision for Pika Wiya clients with mental illnesses, eg some staff from the mental health service attend some case review meetings at Pika Wiya ad hoc.

According to participants, Pika Wiya has about 26 clients with diagnosed major mental illness, all of whom require medication, and many more clients with social and emotional distress. They felt that available services are inadequate for the high prevalence of social and emotional distress among Aboriginal people in the area. Some perceptions regarding the lack of access to culturally appropriate mental health services for Aboriginal people in Port Augusta included:

*“I know the Aboriginal health service ... just that my own personal reflection is that availability to counsellors...you know related to mental health...Pika Wiya, there’s no mental health counsellor. There’s no funded counsellor from a mental health” (PA #4).*

*“... services really being quite depleted in regards to the needs of Aboriginal people in the community. Particularly around issues such as grief and loss, poverty and mental health. Issues such as suicide, accidental and illness-related death, imprisonment are all related to mental health problems and are often in the histories of people who are clients...” (PA #5).*

It was revealed that a mental health worker from the mainstream adult mental health service will see clients at Pika Wiya if requested. Apparently this person does not visit people in the community due to perceived occupational health and safety risks:

*“Pika Wiya actually tried to take him out but he would not go. He just sends out letters and expects clients to come in to him” (PA#8).*

Indeed Pika Wiya staff confirmed that this is in keeping with the organisation’s policy of ensuring the safety of its workers. This was seen as an example of the need to provide a range of accessible and flexible services, not only mental health services, to people in their communities and homes, and not from ‘behind the desk’ in town, as several participants emphasised. The same problem was identified in Copley. One health worker said:

*“One of my concerns is that their like health workers come along and base themselves in the main town, but they don’t actually come out to the satellite communities...where most of the clientele are coming from. I think they need to come out more into the community situations”(P#11).*

It was agreed that more Aboriginal workers should be employed at Pika Wiya as well as mainstream services in Port Augusta. Workers pointed out that lack of resources in all sectors limited their ability to provide adequate staff [16]. One participant thought that it might not be economically viable to employ multiple specialist counsellors eg. in sexual assault or drug and alcohol, but instead recommended employing more workers with good generic skills and the ability to work effectively across different fields. Others spoke of the need for career paths for Aboriginal professionals, particularly in mental health, as an incentive to stay in the workforce.

The special problems faced by Port Augusta workers were discussed, eg. the Pika Wiya focus group revealed that Aboriginal health workers were sometimes concerned about payback from the Aboriginal community if a client dies or if something goes wrong. They also identified a need for cross-cultural training for all workers (Aboriginal and non-Aboriginal) at Pika Wiya and elsewhere to raise awareness of, and skills in dealing with, the cultural diversity of its Aboriginal clientele. The importance of honest and open communication was emphasised by participants, encouraging workers to admit when they do not understand, seek advice and build relationships (P#8).

Copley participants said they need mental health workers and a drug and alcohol service, but there are insufficient funds. Existing workers at Copley have received very little training in these fields, and resort to seeking assistance from a crisis phone line in Adelaide. Videoconferencing to provide mental health services for people in outlying areas was trialed at Leigh Creek hospital, but it was alleged that clients prefer face-to-face consultations. Participants told how the Copley health workers sometimes

drove their clients to Port Augusta to access the specialist services they required.

Feelings of shame and powerlessness limit access, or willingness to access, the few available mental health services. This impacts on individuals and their carers (family members), particularly the grandmothers, who are totally overburdened physically, spiritually, mentally and emotionally, as illustrated by this quote:

*"I think that there's a lot of stigma surrounded, you know, in the Aboriginal community and like with mental illness. Don't want to put their old people away... they don't want to put their family member who's suffering a mental illness or you know...under enormous stress, (or) there's some drug or alcohol (problem)... I've known a person... where a family did that. They put ... it's a shame job to talk about it. Now family's actually paying for it you know, the enormous grief. ...They probably knew that it was there but felt helpless to deal with it, and the way out was for that person to be admitted. Well they made the choice to ... that could keep them alive. (P#4)*

Participants felt that greater effort should be made to demystify mental health disorders in the community to reduce the stigma and encourage people to seek help (PA#5). The steering committee pointed out that Pika Wiya had hosted a seminar in recent years for professionals and community members to increase understanding about social and emotional wellbeing issues for Aboriginal people [16].

Mental health issues for young people, particularly males, concerned participants:

*"(There is) a great frustration (about) the increasing numbers of young Aboriginal males in particular with alcohol and drug problems associated with grief, and also predominance of young males, boys and young men, with an early diagnosis of schizophrenia with psychosis." (PA#5).*

We were told how young Aboriginal men in contact with the criminal justice system at Port Augusta have limited access to services, generally only FAYS and the police. It was suggested that health, recreational, employment and other services and programs could be developed for them as a way of reducing mental health distress and harm.

#### ***Involving carers and other family members***

Participants believed that there should be more emphasis by service providers, particularly non-Aboriginal but also Aboriginal, on providing support to the extended family and carers. They said that families lack support and appropriate information about caring for their relatives with mental health disorders:

*"We don't know enough about how to cope with it" (P#10).*

Participants wanted a support group to help family members, and workshops where they could learn how to deal with the issues they are facing. The community focus group of Aboriginal women discussed how information only flows between the patient and the doctor, and how not sharing this information with other family members makes caring difficult (P#10). However, as other participants mentioned, some people prefer not to share such information, particularly in small communities where people know each other personally as well as professionally. Indeed, a perceived lack of confidentiality in some Aboriginal health services was given as a reason for some Aboriginal people's reluctance to use them:

*"There needs to be carefulness about what is said in the services and who says it. Confidentiality needs to be guarded very, very preciousely."*  
(PA#8)

Poor communication between services for effective and timely discharge planning was identified as a major problem for Copley participants. They told of an instance when home care services were not notified when a client was discharged from an Adelaide public hospital, and how the clients' children were left to make necessary arrangements with the community service providers. Clear guidelines and strict protocols for discharge and post-discharge care planning are needed, because there may be changes to medication, increased need of assistance, injections to manage, etc. The steering committee told how local and state mental health service providers had already recognised this need and had resolved to set up partnerships for streamlined discharge planning protocols [16].

Due to lack of mental health services in the region, clients with crises associated with severe mental illness are sometimes admitted to Glenside Hospital, an adult mental health facility in Adelaide. However, this involves separation and isolation from the family, and money and travel problems for the family. Participants also spoke of stigma associated with being in Glenside, and how some people have experienced rudeness and cultural insensitivity from staff there.

### **General Practitioners**

Pika Wiya Aboriginal Health Service and general practitioners in Port Augusta have initiated a range of activities to bring their services together more effectively and appropriately, including a Social and Emotional Wellbeing Seminar in 1999 [16], combined executive meetings between the Port Augusta Hospital and Pika Wiya (including representatives from the Flinders and Far North Division of General Practitioners and the Director of Allied Health Services), monthly interagency case discussions, and monthly meetings with the Division of General Practitioners. Historically the general practitioners in Port Augusta have been very supportive of Pika Wiya Aboriginal Health Service. Most have been and continue to be very willing

to provide GP services at Pika Wiya when it is understaffed. Currently there are two GPs from other practices who still provide a clinic within Pika Wiya Aboriginal Health Service. Pika Wiya management greatly appreciate this help, and are naturally keen to maintain these good relationships. However, they said that that most general practitioners in the region needed to have a more holistic approach and to encourage their Aboriginal clients to access programs and sessions held at Pika Wiya without fear of poaching.

The interviews uncovered various opinions about the provision of health services from GPs. One carer was satisfied with the level of information she received from the GP in regards to medication use. Another participant reported:

*“The Pika Wiya doctors are very good but the (other) GPs in Port Augusta are not providing a good service. They are reluctant to diagnose psychiatric issues. They’re reluctant to diagnose dangerous issues of threatened self-harm, of suicide and threats, of risk to family members” (PA#5).*

This issue was put differently by the Pika Wiya focus group, who emphasised the pressure GPs work under:

*“One of the local GPs gives out anti-depressants and nothing has changed for these people. The doctor and the client know that grief is not really addressed and there’s pressure on the GPs, even if the GP is trying not to prescribe drugs, to prescribe drugs. Clients get angry with the doctor if the doctor doesn’t prescribe anti-depressants and they do doctor shop. And there is another GP who is known to be prescribing significant amounts of Benzodiazepines. Word gets around...” (PA#8).*

Many participants were dissatisfied with mainstream GP services in Port Augusta. The Aboriginal women’s focus group believed that some doctors do not consider signs and symptoms adequately, do not listen attentively and diagnose too hastily. Because many Aboriginal people are quiet and shy, some GPs presume that they have understood important information. Participants also claimed that some doctors use too many big words, and suggested that doctors need to take time to explain by talking and using pictures.

Cultural awareness workshops were held at least two years ago for mainstream and Pika Wiya health professionals, and these were popular and well attended, according to key informants. Nevertheless, participants told how consultations with GPs may not always be culturally respectful, highlighting the need to reinforce and repeat such training:

*“You feel unimportant because you are Aboriginal” (PA#9).*

Good communication between medical professionals was also emphasised. For example one participant said:

*“When a ... doctor came to Pika Wiya, (the doctor) needs to listen to the Aboriginal people. So do the admin staff and the bosses. Often what Aboriginal health workers ask for, doesn't get dealt with. For instance, the ... doctor didn't listen. And then it's a two-way thing, they (Aboriginal health workers) shut off and they don't want to communicate with the white people.” (PA#8).*

It was alleged that some GPs in Port Augusta will not see people who are thought to be intoxicated, raising concerns about duty of care, eg:

*“... doctors won't see drunk people. They refuse to assess them even though they may be at risk of having a head injury or some other illness. There was a story of ... (some) drinkers and they had a fight and one was hit on the heart area ... and was in a lot pain. His (relative) brought him in and he was referred to the doctor, but because he was drunk... the doctor wouldn't see him and he went outside and fell ... (his relatives) took him to hospital to the other doctors. And that was ... at a GP's practice” (PA#8).*

Pika Wiya staff indicated that, like most other organisations, their service had a policy of calling for help from police before seeing anyone who posed a threat, but that no incidents of this kind had occurred in the last three years.

Continuity of the care relationship was also regarded as an issue. It was alleged that in Copley there is no doctor, but that nearby Leigh Creek has a doctor on 24-hour duty (dividing time between the hospital and the medical service), and they change every two weeks. Although some of these doctors work repeatedly at Leigh Creek there is considerable turnover and hence difficulty in developing the necessary trusting relationships between client and doctor. Problems recruiting and retaining doctors was also an issue for Pika Wiya, and some participants criticised the quality of the patient-doctor relationship in such circumstances. One of the carers said:

*“...they've got about 5 doctors in the surgery. But we haven't got one doctor (at Pika Wiya) ... it's a different doctor every time we go” (PA#2).*

Pika Wiya Despite the turnover of staff, access to patient records is continuous in these settings.

Key informants mentioned that there is not the same turnover among mainstream general practitioners. They tend to establish their practice and stay in the area long term. As a result some Aboriginal people prefer to use general practitioners' services. According to the Aboriginal women's focus group, older people especially tend to prefer their own regular GP. Several participants were concerned about possible breaches of confidentiality in



some Aboriginal health services, including Pika Wiya, and this concern also affected people's choice of GP and health service. However, Pika Wiya staff and the steering committee felt that many of these concerns are based on past practices, and that recent changes in the service mean that such worries are outdated. Nevertheless the steering committee agreed that public perceptions, even if erroneous, should be taken seriously and addressed by more vigorously promoting Pika Wiya's policy to provide culturally appropriate and confidential services to all Aboriginal people.

It was alleged that people who choose to use mainstream GP services may miss out on important services at Pika Wiya (transport, medication subsidies and delivery, etc) even though these government funded services are meant to provide for all Aboriginal people. Pika Wiya staff believe that they can provide these services to anyone who registers with them, even if they do not normally see Pika Wiya doctors, and this is confirmed in their annual report [17]. However, this still leaves Aboriginal people who do not wish to register with Pika Wiya without equal access to services.

Emergency admissions to Port Augusta hospital were also identified as a problem, as there is a pool of doctors rostered on call from both Pika Wiya and private general practice. Emergency clients see whoever is on call, and so Pika Wiya clients will not necessarily see a Pika Wiya doctor who knows their particular circumstances, and where trust may have been established. The need for better coordination and communication between services, although previously identified by local stakeholders [16], remains.

## **Medicines**

### ***Types of medication***

Two of the carers said that the persons they looked after took prescribed medication regularly. Another carer did not know if the person she cared for was taking any medication, but thought he needed medication as his behaviour was often hyperactive and erratic. Medications mentioned by participants included Panadeine Forte, Mersyndol, Aspirin, Aropax, Insulin, anti-hypertensives and anti-inflammatories. One described her medications by shape and colour, but believed she had good understanding of her medication (a major finding from previous work by one of the research team [20, 21]).

### ***Managing and monitoring medication***

Managing medication was reported as a problem for many people, due to physical disability, lack of understanding and confidence, or because individuals did not prioritise medications as one of their health issues. For example, one participant said that some people do not bother about taking

their insulin even though it is easy to administer. Another travelled to a hospital in Adelaide to learn about insulin management, but worried about administering it at home due to poor eyesight. Participants talked about requiring assistance with managing medications from district nurses. Elderly participants found it particularly stressful to adjust their lives to “*white man’s ways*” (PA#10), particularly in regards to medication for chronic diseases. According to these participants, most diseases could be managed or avoided with bush food and traditional remedies.

In Copley, health workers can fill dosette boxes for clients, following instructions on the tablet box. A senior nurse from Copley identified problems with dosettes, for example people tend to forget to take dosette boxes with them, or they drop the boxes and put tablets back in the wrong spots. Community pharmacists prepared Webster packs (ie sealed bubble packs) for 3-4 clients in Copley for whom a managed medication system is appropriate. The pharmacist mentioned that there are also problems with Webster packs, and that appropriate systems are used depending on the needs and preferences of individual clients and communities.

Copley health workers identified the difficulties they faced and compromises they made in monitoring compliance with medication. For example, they told how one client, an elderly man with multiple health problems and dependent on large amounts of medication, was assisted by an untrained Meals on Wheels volunteer to check his tablets on weekday mornings, but was left to his own devices in the evenings and on weekends.

Participants agreed that a range of health and community workers had some involvement in their clients’ medication, and that they would benefit from medication management training. This issue also emerged in other regions of SA where this project has been conducted, and was confirmed by a SA-wide survey of workers, also part of the project. Pika Wiya, Port Augusta Hospital pharmacy, community pharmacists and SACCRH recently developed and delivered a training course on better understanding and use of medications for health workers from Pika Wiya and its outreach clinics who found it valuable to their practice [39, 40]. The course will be repeated soon, and will be updated yearly by pharmacists or more often if required. The course is also being modified as a self-directed learning package for Aboriginal health workers elsewhere [39, 40]. However, many other workers, drivers or volunteers from other organisations who handle, transport or otherwise manage medications are still lacking knowledge and skills for safe, quality use of medicines.

### ***Feelings about medication***

Participants who understood what their medication was for, and felt that it was the right one for them, had a positive attitude towards taking that

medicine. These were people who had believed they had received adequate information from their doctor and were confident that the prescribed medicine was good for them. However, it was also reported that clients do not always receive adequate explanation or encouragement from doctors regarding medications:

*“And the doctors, the GPs, often don’t help them to manage their medications, either in the physical sense of managing or in the psychological and educational sense” (PA#4)*

Some other participants did not trust doctors and therefore did not take their prescribed medications.

Several participants did not know what they were taking, and it was suggested that language issues might contribute to this lack of knowledge and understanding. A coordinator working with Aboriginal families stated:

*“I mean it’s just that sometimes Aboriginal people are disadvantaged because of the language. ...For many, English is their second language, maybe third or fourth...and literacy is a problem...so they don’t ask or they don’t do things.” (P#4)*

One participant told how people with mental health problems may become aggressive or depressed from not taking their prescribed medication. In contrast, others mentioned moodiness, out-of-control behaviour and risk of self-harm when taking medication (the circumstances were not elaborated further).

### ***Cost of medications***

Cost of medication did not concern most participants who believed the medications they were taking would help them. The cost of medicines is heavily subsidised for registered clients of Pika Wiya and its outreach clinics. However it can be expensive for clients with chronic physical diseases, as well as mental health problems, to buy all the medications they need. This is a problem especially for Aboriginal patients and carers who choose not to use Pika Wiya and are therefore unable to access the subsidy, and as a result might do without necessary medication.

*“ Often people cannot afford to purchase their medicines because they need food or other, there are other priorities in their daily life.” (PA#5).*

Legislation (\$100) to enable Indigenous people in remote areas to obtain the medicines they need at no charge has been trialed in several areas. Copley and Nepabunna has a small stock of non-prescription items and Pika Wiya’s pharmacist is developing a limited formulary of medicines that can be dispensed by health workers in those clinics. Pika Wiya in Port Augusta has a small pharmacy imprest so that clients visiting the doctor there can collect certain medicines on-site without having to fill a prescription at a chemist shop.

As there is no doctor or registered nurse on call at Copley/Nepabunna, medications cannot be dispensed there after hours, and so residents have to go to Leigh Creek hospital. It was also reported that some people from Copley and Nepabunna were charged the co-payment fee when filling their prescriptions at Leigh Creek pharmacy. However, these allegations were disputed by Pika Wiya staff who believed that all Aboriginal people at Copley and Nepabunna are registered clients of Pika Wiya and therefore eligible for subsidised medicines. From the divergent accounts obtained from participants it is clear that some people perceive, perhaps erroneously, that Aboriginal people in outlying areas may be disadvantaged, and could therefore be at risk of not presenting for much-needed medication and health assessment.

#### ***Delivery of medications***

Some participants had run out of medication, as their local chemists did not provide after hours services. Pika Wiya does deliver medications to those of its clients who need this service, but delivery times were reported to be inconsistent and therefore unsatisfactory for safe medication management. Consequently one client (with diabetes and heart problems) would sometimes go to bed without having his tablets, or would eat before medications were delivered. His carer said:

*“At 8 o’clock and 9, between 9 and 10, maybe sometime 10 o’clock before Pika Wiya come with the tablets then and he’s already had his breakfast. And that’s the problem that I’m facing. I thought we take our tablets before meals - most of the time” (PA#3).*

This carer had told Pika Wiya about the problem, but they were not able to ‘change the system’. Key informants told how Pika Wiya has recently improved its medication delivery system for certain clients who need close supervision, and has initiated monthly case reviews for clients at risk. Pika Wiya staff are proud of their delivery system, believing it to be the best in the state.

#### ***Sharing and storing medications***

The participants said they did not share medications (only one carer reported using the same blood pressure medication belonging to the patient). The carers said they stored medications safely in a container out of children’s reach. However, key informants said that sharing is central to Aboriginal cultural values, and that crowded households often provided little security to store medication safely. A woman from Copley received her medication from the chemist in a little locked box.

### **Mental Health (social and emotional well being)**

#### ***Understandings of mental health***

Participants had various understandings of mental health and mental illness. One carer could not define mental health. Another did not know what

mental health condition the person she cared for suffered from. Local Aboriginal women listed the following terms in relation to mental illness:

*“the mind is not right, worries, anxious, stress, misbehaving like drunk, don’t communicate, smoking dope, loneliness, crazy, confused” (PA#9).*

Another participant explained mental illness like this:

*“Something to do with their emotions. It has to. Um, not thinking right, brain damage. Not so much brain damage, but you know, they don’t, they can’t, they can’t put anything into focus or can’t, people with mental health problems, I don’t think they can put anything into focus” (PA#3).*

The female focus group believed that genetic factors were involved in some mental illnesses. They talked about someone who misused alcohol and drugs to disguise a mental illness they considered to be genetic:

*“the kid come from that same line of family” (P#10).*

A majority of participants associated mental health problems with European contact and one stated:

*“I look at mental health and I’m goin’ with the old people too, but I look at, ‘cause I studied as I grew up, I was studying all the old people and how they coped with white fellas’ ways. And I could see that they weren’t coping. They just weren’t coping with white fellas’ ways” (P#10).*

### ***Social and emotional wellbeing issues in Port Augusta region***

Participants identified several social and emotional well being problems in their community. The main issues mentioned were misuse of drugs and alcohol, grief and loss, domestic violence, multiple social and health problems, and certain diagnosed mental illnesses (schizophrenia, bi-polar illness and depression). As mentioned earlier, they talked about perceived increase in young Aboriginal males with alcohol and drug problems, and of schizophrenia and psychosis associated with heavy use of cannabis. Domestic violence was mentioned in relation to a woman who had been misdiagnosed as suffering from a mental illness and given medication for it, when in fact she was suffering grief and emotional problems due to the violent situation at home.

In Copley people experiencing mental health problems were particularly seen after hours and on weekends, usually exacerbated by drug and alcohol use. Youth depression was seen as a particular problem, but it was reported that only a minority are diagnosed and treated because many Aboriginal people are reluctant to access mental health services, preferring to rely on informal help from family. Youth suicide and self-harm was also reported, but mostly in the outlying communities. In Port Augusta the women’s group identified youth suicide as a big problem, and said it happened in two year cycles (P#9).

The poor general health of many Aboriginal people and their families impacted greatly on their social and emotional wellbeing. Physical problems such as losing a limb, traumatic injury, snake bite, chronic diabetes and renal disease, waiting for an organ transplant, gangrene and poor eyesight were mentioned as contributing factors to mental health problems, particularly severe depression.

Child and adult sexual abuse was identified as a hidden and shameful issue, and there is little local professional support available for the victims and their families, especially mothers of young girls who have been sexually abused. Participants said that provision of services for these people are inadequate and inappropriate. They said that the women's health service providers are not specialists in sexual abuse and are white, and Pika Wiya's Aboriginal social and emotional wellbeing counsellor is male leaving female victims without any actual choice to the types of services they urgently require. Child protection agencies and FAYS were viewed with suspicion by some people due to past practices of their predecessor bodies in removing children from families deemed unable to care for them properly. A key informant spoke of a number of young people who were removed as children and are now young parents themselves, and who reject FAYS attempts to support them to cope with their own family issues. This opinion was supported by the Pika Wiya focus group who claimed that Aboriginal people do not like FAYS, and prefer to use Pika Wiya for family support.

#### ***Effects of mental health problems on families***

Mental illness was reported to be frequently unrelenting, very distressing to individuals and their families, and their distress is compounded by poorly managed medication, and inadequate service and support, as the following episode illustrates:

*"A young woman, for instance, with a huge psychiatric (illness)...Police were called and used electronic shock prods to control her and unfortunately this exacerbated her already out of control behaviour and she flattened (them). The family of course were very distressed and it took 30 minutes for another group of police to come who in fact managed the situation very well. They just sat down with her and talked quietly and she calmed down. It turned out that she had not taken her medication for her diagnosed mental health problem. She had had a medical assessment but the mental health team had chosen not to provide ongoing care for this young woman. One can only assume why. ... It was too much for the family to cope ... no services ...had been provided for her and there was no respite offered to the family. The (family members were) extremely distressed and in fact FAYS has had to be dealing with (them). The ...house was damaged and that had to be paid for and again FAYS had to come in to help with that. And Pika Wiya was*

*wonderful in the way it helped the (family members).... So all in all, an out of hand situation took up a lot of resources for what should have been managed better. As she said, the non-Aboriginal mental health team was supposed to care for her but do not and have not and currently Pika Wiya and FAYS are trying to help her and the family. Pika Wiya is very under resourced and underskilled to do this for psychotic patients and clients. They do try and help her take her medications. They deliver them to her but they can't make her take them and currently she's denying her diagnosis and refusing, therefore refusing to take the medication. This is an ongoing dangerous situation for her and the family (PA#5).*

### **Traditional practices**

Traditional practices for addressing mental health issues were discussed. Aboriginal participants felt that traditional Aboriginal healers (Ngangkari) can help by reconnecting spirit and body. One non-Aboriginal key informant was not aware of traditional practices, but felt they might be hidden away from non-Aboriginal people anyway. The Pika Wiya focus group said that Pika Wiya Health Service has occasionally brought in Ngangkari and paid for their services, or has arranged for people to return to their homelands to consult traditional healers. This system is being trialed at Pika Wiya with help from the Department of Human Services, and has not yet been formally evaluated. The Pika Wiya focus group said that it was more usual for Aboriginal community members to consult with traditional healers privately if and when they wanted to. It was generally agreed that people need to be able to make the choice. Further, it was agreed that mainstream health professionals need education about the value of traditional healing practices.

## **Alcohol and Other Drugs**

### **Types of substance misuse**

Participants identified addiction to alcohol and drugs as having an enormous impact on Aboriginal culture, and agreed that substance misuse was closely linked to socio-economic disadvantage and mental health issues (PA#4). They agreed that people often drink or use drugs to forget the multiple problems in their lives, but that the cycle continues. Participants were particularly concerned about alcohol addiction and its association with violence (P#10). It was alleged that binge drinking on weekends is reflected in increased admissions to hospital due to injury (P#11).

Alcohol and cannabis are commonly used and it was said that these social drugs suit Aboriginal culture because of the sharing component. The peer pressure to smoke cannabis was discussed, and it was alleged that some children are smoking cannabis with adults and families. Participants said that solvent misuse also occurs among some children, it used to be petrol,

now it is paint and glue. They felt that solvent sniffing was behaviour introduced from outside the area. Illegal prescription drug use was also identified as an issue in Port Augusta, particularly Rohypnol and Valium. According to participants injecting drug use (heroin, amphetamines) is rare. However there is a very active clean needle and syringe program at the Port Augusta Sobering-up Unit indicating this is a covert activity.

It was agreed that alcohol is a major problem, particularly under-age purchasing, under-age drinking and binge drinking. As a result of the 'dry zone' laws, which were introduced in the mid-1990s, this alcohol misuse often occurs out of the public eye, eg at home or in the camps, in car-parks and on the edge of dry zones, placing drinkers and others at risk of injury and other problems and reduced access to help.

#### ***Effect of substance misuse on carers and families***

Participants believed that substance misuse impacts on the authority usually commanded by older family members. They said that people under the influence of alcohol or drugs do not respect their Aboriginal elders. Participants talked about a disintegration of family and social structures because the main value-system of respect is broken down.

It was reported that some medications eg Panadeine Forte and Mersyndol, were used to get a 'buzz', often in conjunction with alcohol and cannabis. Carer participants found the combination of alcohol use and prescribed medicines very stressful for families. For example, the focus group of women talked about someone who needed respite from the stress experienced when her mentally ill relative mixed prescribed medication with excessive alcohol. Participants mentioned Pika Wiya initiatives such as men's bush camps as ideal in relieving carer stress, and providing excellent rehabilitation for the users (P#10), and these positive sentiments were reinforced by the steering committee. However it was not clear if these initiatives have been formally evaluated, how often they occur, or if they have been modified for carers.

#### ***Drug and alcohol services***

When intoxicated clients attend Pika Wiya Health Service, the workers call the local council's Mobile Assistance Patrol to take them to the Sobering Up Unit. However, the Sobering Up Unit does not enable family members to support a relative who is 'drying out'. Furthermore, participants said that there was little communication or coordination between the Mobile Assistance Patrol and other services, particularly Aboriginal services:

*"The mobile patrol and sobering up unit people do their own type of treatment."*



This is of concern because the Pika Wiya focus group saw alcohol and drug issues as the major problem for their clients. The Mobile Assistance Patrol and Sobering Up Unit workers recognise their need for further training, and as part of this project the chief investigator has since conducted a special 3-day accredited course on caring for intoxicated people safely. Feedback from the attendees was very positive. All said they now use the knowledge gained in their work, particularly in regards to giving accurate advice to clients about Hepatitis C and consequences of drug and alcohol misuse, supporting the clean needle/syringe program and actively improving their own workplace safety.

Participants wanted an Aboriginal drug and alcohol rehabilitation centre in Port Augusta. Apparently, currently available rehabilitation programs (only two live-in programs) are located in Adelaide and are not culturally appropriate. Only one has a program that includes children with the client/parent, and both programs are too far away from Port Augusta, which makes it difficult for clients to take part, and families to visit.

The Pika Wiya focus group suggested setting up local programs based on clients' and families' needs. They identified a need for a drop-in centre, counselling, detoxification and rehabilitation for alcohol and drug use problems. This would include special services and programs, activities, social and cultural activities and work activities (PA#8). The steering group said that Pika Wiya has started a weekly counselling service for people with alcohol problems. It was agreed that a coordinated approach that addresses the underlying social, emotional and cultural issues that influence mental health and substance misuse is needed. Such programs would also relieve Aboriginal health workers from all the ad hoc out of hours work.

A number of the women participants had been heavy drinkers in the past and some had never been drinkers. They wanted help to remain alcohol free, and also to deal with their family members who are heavy drinkers, whether they be children or partners or older people. These women are often the ones that have to do all of the basic management of these complex situations, while still trying to maintain their own health, safety and wellbeing.

#### ***Difficulties for people with mental health problems***

Carers emphasised the difficulty that people with mental health problems have in looking after themselves. They highlighted issues with maintenance of personal hygiene, understanding of money, paying bills and living on their own. Some of the people they cared for had need of supported accommodation to relieve the burden on carers and other family members, including children.

## **Discussion and recommendations**

This project explored issues, contexts and needs affecting safe medication management by Aboriginal people with mental health problems and their carers in the Port Augusta region. The following broad themes were identified:

- Need for accessible, affordable and culturally appropriate mental health services
- Getting, managing and taking medication
- Coordination of services and integrated pathways of care
- Education

Interestingly, similar issues were uncovered in our pilot study [28], and in our research in other parts of South Australia and from a SA-wide survey of health professionals (both undertaken as part of this QUMEP project - to be reported separately). This consistency of findings from different areas, and with use of multiple qualitative and quantitative research methods, indicates the credibility of the results and demonstrates the trustworthiness and validity of the research approach.

The research team, Port Augusta Steering Committee, the Aboriginal women's group in Port Augusta, and other stakeholders discussed the issues revealed by the data, and collaboratively developed the report and recommendations. The process was iterative and consultative, with successive drafts being progressively refined and modified. It is clear that many of these issues are fundamental to Aboriginal well being, and can only be addressed through sustained commitment of resources and energy. It is also evident that Pika Wiya and other health and community services in the Port Augusta area are providing an excellent service, despite limited resources and enormous demand, and are committed to continuous quality improvement. However there are a number of key issues which could be solved through creative redirection of resources/personnel, modifications to policy and practice, collaboration, better integration of services, targeted education and training, and lobbying for, and accessing, additional funds.

It is notable that although many of these issues and recommendations have been identified previously and reported widely, and national and regional strategies and implementation plans have been formulated [16-19, 51], there has been little evidence to date of improvement in living standards, mental health and quality use of medication for Aboriginal people. This is a major concern.

### **Need for accessible, affordable and culturally appropriate mental health services**

The data affirmed that there are extensive social and emotional well being problems for Aboriginal people in Port Augusta, Nepabunna and Copley, and

that existing services are of a high standard but struggle to meet needs adequately. It was recognised that existing mental health resources and services for Aboriginal people in the region are not always identifiable, affordable, accessible, equitable or culturally appropriate.

#### Recommendations

1. Continue and enhance support for Pika Wiya Aboriginal Health Service and other local health and community services to promote mental health and assist all Aboriginal people with social and emotional wellbeing problems.
2. Continue and enhance support for Pika Wiya Aboriginal Health Service, Port Augusta Hospital Pharmacy and other local health and community services, including services to intoxicated people, to promote safe medication management by workers who have a role in transporting, handling, storing, collecting, providing and/or supervising the use of medicines by Aboriginal people with mental health disorders, including alcohol/drug problems.
3. Establish a mental health facility in Port Augusta to provide in-patient, out-patient, acute and long-term care for Aboriginal and non-Aboriginal people.
4. Establish an alcohol/drug rehabilitation unit and detoxification service at Port Augusta.
5. Establish a 'safe house' for Aboriginal people with mental health problems (including substance misuse problems) and families/carers.
6. Increase the Aboriginal workforce in health and community services, particularly multi-skilled health workers, counsellors and managers of both genders, and structure services so that individuals and the community are provided with holistic care.
7. Facilitate and encourage mainstream health professionals and other workers to visit clients and families at home and in the community.
8. Continue to support the professional education of GPs and other health and community workers, non-Aboriginal and Aboriginal, on culturally respectful practices, service provision, collaborative care and communication.
9. Employ sufficient numbers of trained male and female Aboriginal mental health workers at Pika Wiya and in the mainstream Port Augusta mental health service.
10. Establish support groups and workshops for carers, children and other family members of Aboriginal people with mental illness and alcohol/drug disorders.
11. Ensure equitable provision of services (eg medication subsidy and delivery, transport assistance) to all Aboriginal people in the region, particularly those in outlying communities and those who choose not to use Aboriginal health services.

12. Reassure the Aboriginal community in the Port Augusta region that Pika Wiya and other health services are committed to providing confidential professional services to all Aboriginal people.
13. Continue and extend funding arrangements for registered traditional healers.

## **Getting, managing and taking medication**

It is clear that some Aboriginal people with social and emotional well being problems in the Port Augusta region have difficulty accessing affordable essential medicines, particularly if they live in outlying areas, or if they obtain prescriptions from GPs other than those at Pika Wiya. It was agreed that ensuring that Aboriginal people with mental health disorders get and take their medications in a timely manner would considerably improve their health and wellbeing, and that of their carers and other family members. Better medication management might also reduce emergency hospital admissions and other crisis interventions. Some of these issues may be addressed through services working together better (see elsewhere in this section).

### **Recommendations**

14. Appoint a trained Aboriginal health worker to be the medication coordinator for Pika Wiya, the mainstream Mental Health Service in Port Augusta and the Flinders and Far North Division of General Practice. The medication coordinator would attend case review meetings, and visit clients at home as needed, and make sure that medicines are transported and delivered safely and on time and managed safely.
15. Develop strategies to ensure that Aboriginal clients can obtain prescribed medicine after hours or in locations remote from Pika Wiya without incurring additional fees.

## **Coordination of services and integrated pathways of care**

Aboriginal people with mental health problems and their families deal with many health and social services, locally and in Adelaide. Poor communication and inadequate care-planning and coordination between the various services and with the family can compromise health and wellbeing of their clients. This is particularly important for clients being discharged home to a rural/remote area from a health facility in Adelaide. It is also pertinent to clients on release from detention.

### **Recommendations**

16. Develop strategies to improve collaboration, coordination and communication between: Pika Wiya and its outreach clinics, local GPs

and hospitals, mental health facilities and hospitals in Adelaide, the mental health service in Port Augusta, and other community services. Clear communication protocols and pathways of care, and unambiguous roles and responsibilities are urgently needed.

17. Involve carers/families and community services in planning for discharge from hospital.
18. Develop special programs and support services for young and older men with mental health disorders and/or substance misuse problems who are on parole, under treatment orders, or otherwise involved in the justice system.
19. Develop timely, local, gender specific and culturally appropriate sexual assault and support services for Aboriginal people who have been sexually abused.

## **Education**

The need for more education and training for Aboriginal health workers and other workers who handle medications for Aboriginal people with mental health problems was another major theme. It was recognised that Aboriginal health workers and counsellors need very broad skills that encompass mental health (social and emotional wellbeing), alcohol and drugs, and medication management, because they are required to deal with diverse and complex health problems, often with limited backup support. Specific training needs of other groups were also suggested.

### **Recommendations.**

20. Support and facilitate accredited training and career paths for Aboriginal health and community workers, with the aim of broadening their skills to match community demand and expectation, and their personal career goals.
21. Provide family wellbeing training for health care professionals, both Aboriginal and non-Aboriginal.
22. Support and inform key groups in the region about current initiatives in offering training in safe medication use to Aboriginal health workers provided jointly by Pika Wiya and Port Augusta Hospital pharmacists
23. Offer safe medication management training to the wide range of workers (eg. drivers, health workers, aged care workers, youth workers, police, substance misuse workers, shelter workers, volunteers) who are involved in transporting, giving or managing medications.
24. Continue to provide regular mental health training and drug and alcohol education for FAYS and other community workers as there is a large turnover of staff. This should include managing personality disorder conditions and situations as well as other intoxication, addiction and major psychiatric problems.
25. Train the Mobile Assistance Patrol and Sobering-Up Unit staff, and other substance misuse workers, to assess and care for intoxicated people safely.

26. Provide culturally appropriate community education to demystify mental health issues, reduce the shame, and increase access to key services within the Aboriginal community.
27. Provide training that has clear pathways into, and articulates with, accredited culturally appropriate education programs such as those provided by Spencer Institute of TAFE and Flinders University School of Nursing & Midwifery.

## **Early outcomes, current activities and future plans**

In direct response to the findings and recommendations of the project in the Port Augusta region and elsewhere in SA, there have been several initiatives, as described below. At the same time a number of related but complementary activities are in progress, and these are also discussed.

Response to Recommendation 17 (Involve carers/families and community services in planning for discharge from hospital).

In response to the findings of this SA-wide project, members of the research team are negotiating with the Eyre Peninsula Division of General Practice, Port Lincoln Aboriginal Health Service and Mental Health Services in Adelaide to develop and evaluate protocols and processes for better coordination of Aboriginal mental health care and service delivery. They have been awarded competitive grant funding to continue this work in 2003. Services in the Port Augusta region might consider joining this group in future, to enhance services for Aboriginal clients with mental health problems and their families. As the focus of this work is on coordinating mental health care and related community services, it complements a number of State and Commonwealth initiatives around systems of care for chronic disease. Health care services in the Eyre Peninsula and Port Augusta regions are already involved in some these initiatives [41]. The experience, understanding of the issues, and networks gained through this involvement increases the potential for success of the new coordinated mental health care initiatives.

Response to Recommendation 20 (Support and facilitate accredited training and career paths for Aboriginal health and community workers, with the aim of broadening their skill base to match community demand and expectation.) The Flinders University School of Nursing & Midwifery offers a range of accredited multi-disciplinary short courses that articulate with formal training programs for Aboriginal health and community workers within the University as well as Spencer Institute of TAFE and other accredited educational programs. Its eye health, diabetes, continence, injecting drug use and blood borne diseases, alcohol/drug counselling, drug and alcohol and mental health comorbidity, and safe medication management courses are

all suited to, and popular with, Aboriginal workers. Topics are delivered as intensive workshops in Adelaide and by negotiation regionally, and are also available by flexible delivery (distance education). Workers from Port Augusta region are welcome to attend. The local Aboriginal research assistant in this project received training on research-related skills as part of this project.

Response to Recommendation 22 (Offer medication management training to the wide range of workers eg. drivers, health workers, aged care workers, youth workers, police, substance misuse workers, shelter workers, volunteers who are involved in transporting, giving or managing medications).

The need for this training emerged from the project's findings in other parts of SA, and was confirmed by the survey of workers also conducted as part of this project. An important aspect of this SA-wide research was to implement and evaluate selected strategies developed in response to findings. Therefore the School of Nursing & Midwifery at Flinders ran an intensive 3 day course on safe medication management for Aboriginal mental health in September/October 2002 as a part of the project. This course was designed not only for Aboriginal health workers, but also for a variety of other workers including drivers, substance misuse workers, and mental health workers, who need to know how to safely transport, handle or otherwise manage medications. Although no workers from Pt Augusta were able to attend on this occasion, they are welcome in future when the course is run in 2003. The course complements the medication management and awareness course for Aboriginal health workers that was developed by Pika Wiya, Port Augusta Hospital pharmacy, community pharmacists and SACCRH, and presented to Aboriginal health workers from Pika Wiya and its outreach clinics in 2001 [40].

Response to Recommendation 23 (Continue to provide regular mental health training and drug and alcohol education for FAYS and other community workers as there is a large turnover of staff).

As part of this project an accredited 3-day intensive drug and alcohol and mental health comorbidity course was offered to Pika Wiya workers at Port Lincoln in June 2002, but they were unable to attend. It is planned to run the short course again in 2003 and workers from Port Augusta, Nepabunna and Copley will be invited to attend.

Response to Recommendation 24 (Train the Mobile Assistance Patrol and Sobering-Up Unit workers to assess and care for intoxicated people safely). As a direct result of the project in this area the Port Augusta Substance Misuse Service requested specific alcohol and drug training for Sobering Up Unit, Mobile Assistance Patrol and other community workers. A 3-day intensive course on assessing and caring for intoxicated people safely was presented by the Flinders University School of Nursing & Midwifery under

the coordination and guidance of the chief investigator in May-June 2002. The program included the DHS-accredited clean needle and syringe course. The course was very well received and a formal evaluation on completion indicated that participants had gained better understanding of how to practice safely in these high risk workplaces, and accurate information to pass on to their clients.

Response to Recommendation 25 (Provide culturally appropriate community education to demystify mental health issues, reduce the shame, and increase access to key services within the Aboriginal community).

As part of this project the research team in collaboration with Port Lincoln Aboriginal Health Service has applied for a grant for community and workforce education programs on the topic. The team has offered to help Pika Wiya or other services in the Port Augusta region with similar funding applications which build on the existing related programs in the region.

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## **Appendix 1.**

### **Port Augusta Steering committee**

Ms Maxine Austin, Kunga Tjutaku Ngura, Port Augusta

Mr Garnet Brady, Aboriginal Health Unit, Flinders and Far North Health Service

Mr Brian Butler, Aboriginal and Torres Strait Islander Commission, Port Augusta

Mrs Denise Champion, Port Augusta

Mr Malcolm Champion, Aboriginal Liaison Officer, Royal Flying Doctor Service of Australia (Central Section) Inc

Mr Andrew Clark, Wesley Uniting Mission

Sarah Anthoney, Pharmacist, Port Augusta Hospital and Pika Wiya Aboriginal Health Service, Port Augusta

Ms Geraldine Davis, Women's Health, Flinders and Far North Health Service

Executive Officer, Community Care, Port Augusta

Dr Charlotte de Crespigny, Professor of Nursing (Alcohol and Other Drugs), School of Nursing & Midwifery, Flinders University

Mr Greg Haines, Aboriginal Prisoners and Offenders Support Services Inc, Port Augusta

Ms Charmaine Hull, Child and Adolescent Mental Health Service, Flinders and Far North Health Service

Mr Frank Jackson, Pika Wiya Aboriginal Health Service, Port Augusta

Mr John Lang, Victim Support Services, Port Augusta

Dr Iain McIntyre, Medical Director, Division of General Practice, Port Augusta

Mr Malcolm McKenzie, Tji Tji Wiru Youth Service, Davenport Community Council, Port Augusta

Ms Carol Anne Stanborough, Adult Mental Health Service, Flinders and Far North Health Service

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Mr Michael Turner, School of Nursing & Midwifery, Flinders University

Ms Marie Williams, Port Augusta Substance Misuse Service

Mr Garry Wright, Pika Wiya Aboriginal Health Service, Port Augusta

Ms Angela Russell, Pika Wiya Aboriginal Health Service, Port Augusta

Ms Maxine Austin, Kunga Tjutaku Ngura Women's group, Port Augusta

Ms Julie Wright, Kunga Tjutaku Ngura Women's group, Port Augusta

# Attachment 2

## Report on research conducted in the Port Lincoln Region

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**This report was prepared by:**

- Inge Kowanko
- Charlotte de Crespigny
- Helen Murray

**Also involved in this project were:**

- Anita De Bellis, Mette Groenkjaer, Mike Turner and Sharon Cruse from Flinders University
- Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council Inc. (SA)
- Port Lincoln Steering Committee comprising staff of Port Lincoln Aboriginal Health Service and other local health services and community organisations.

### Acknowledgments

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Kowanko, Inge

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## Introduction

Past and ongoing racist policies and practices have resulted in profound and prolonged grief, disempowerment and social disadvantage for Aboriginal Australians. This has led to widespread social and emotional wellbeing problems, and multiple physical, spiritual and mental health disorders [1-6]. The ongoing burden of living with such complex health problems, or caring for someone with these problems, places inordinate strain on the physical and mental health and wellbeing of individuals and the coping capacity of the Aboriginal community as a whole. Sadly, despite numerous inquiries, reports, recommendations and strategic plans [7-12], Aboriginal Australians are still the sickest and poorest in the nation [3, 13].

Of particular concern is the unrelentingly high prevalence of mental health problems among Aboriginal people. Recent national statistics [3] indicate that compared to non-Indigenous Australians, Aboriginal people are hospitalised more often for mental or behavioural disorders and are twice as likely to die from a mental disorder. Furthermore Aboriginal people have disproportionately high rates of assault, suicide and incarceration. It should be remembered that from an Indigenous perspective mental health is a socially constructed concept that incorporates the spiritual, social, cultural, and physical dimensions of life, intertwined with adverse economic and political conditions [14]. Consequently, to be influential, reports and plans relevant to Aboriginal mental health must prioritise wellness and promote holistic culturally informed approaches to healing [5, 8, 10, 15, 16]. However current South Australian mental health plans [17-20] may not yet adequately address these critical Aboriginal-specific issues. Anecdotal evidence suggests that these plans were made without adequate consultation with Aboriginal groups or regional input. However, local service providers, eg Port Lincoln Health Services Inc, Eyre Regional Mental Health Services and PLAHS have developed strategic, business and implementation plans for improving service provision to Aboriginal people in the Port Lincoln and Eyre Peninsula area [12, 21-23].

Safe and effective medication use by people with mental health problems is a major issue, particularly if there are coexisting health problems. Social, health and economic issues associated with the use of medications include intoxication, excessive use and dependence, adverse drug reactions, side effects, drug interactions, hospital admissions, accidents and falls, re-incarceration, misdiagnosis or exacerbation of dementia and other conditions, and psychological effects of polypharmacy [24-26]. The combination of prescribed medications together with other substance use, eg over the counter medicines, illicit drugs or alcohol, can compound the physiological, psychological and social problems of mentally ill persons [27]. National policies and strategies for the quality use of medicines have

been formulated [28, 29] in consultation with consumers [30], professionals, government and industry. The Commonwealth also funds a range of programs to improve quality use of medications through the Quality Use of Medicines Evaluation Program (QUMEP) [31].

There is little research on medication use specific to Aboriginal cultures, apart from earlier studies from this research team [24, 32] which highlight problems due to cultural issues, limited access to information and support, sparse economic resources, lack of education, differences in understanding, personal resources and skills. Other literature has focused on prescribing rates [33], compliance [34], the importance of good communication [35, 36], workforce development [37], pharmacy services [38] and integration of services [39, 40]. Although it is agreed that substance misuse and polydrug use have major negative impacts on health [41, 42], there is little evidence of sustained improvement in health outcomes resulting from the dozens of programs aimed at addressing these issues among Aboriginal people [41, 43]. The lack of literature highlights the need for research to inform policies, health promotion, education, and practice guidelines for safe, effective medication management for Aboriginal people with mental illness.

## **Aims and objectives**

This research is part of a large SA-wide project entitled “Better medication management by Aboriginal people with mental health disorders, their carers and other family members”, funded by the Quality Use of Medicines Evaluation Program through the Commonwealth Department of Health and Aged Care. The research was conducted by a partnership of investigators from the Flinders University School of Nursing & Midwifery and the Aboriginal Drug and Alcohol Council (SA) Inc, in collaboration with Aboriginal communities and other stakeholders across SA, including metropolitan Adelaide, Port Lincoln, Coober Pedy, Riverland and Port Augusta. This paper reports on the component of the project conducted in Port Lincoln region.

The aims of the SA-wide project were:

1. To explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications, using multiple methods and in multiple locations.
2. To recommend strategies to improve quality use of medicines by this group, informed by the findings.
3. To implement and evaluate selected recommendations.

The goal of the Port Lincoln component of the project was to address these aims in Port Lincoln and the surrounding Eyre Peninsula region.

## **Participants and methods**

### **Research approach**

A collaborative approach was taken involving a partnership between the investigators from the School of Nursing and Midwifery at Flinders University and the Aboriginal Drug and Alcohol Council (SA) Inc. The research was planned and conducted in consultation with a steering group of Aboriginal and mainstream service providers and Aboriginal people from Port Lincoln, to ensure that the research was responsive to the needs of the Aboriginal community and conducted in a culturally acceptable manner. The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of SA. The research conformed to the NHMRC guidelines for ethical Indigenous research [44]. It was also deemed appropriate by the Board of Management of the Port Lincoln Aboriginal Health Service (PLAHS), the local host Aboriginal service with whom we worked.

### **Steering committee**

A local steering committee comprising the research team, representatives of Aboriginal groups in the Port Lincoln and surrounding areas, and those who provide health and social services to the client group and their families. The committee was convened in 2001 to guide all aspects of the research (Appendix 1). The steering committee met 4 times over the next 2 years. The team maintained regular and frequent contact with the director and staff of PLAHS over this time. The steering committee was invited to advise on ethical and practical issues regarding data ownership and security, recruitment and training of an Aboriginal research assistant acceptable to local Aboriginal communities, engaging potential community participants, drafting and piloting the interview guide, following up on issues raised by the local Aboriginal research assistant on behalf of anonymous interview participants, and draft reports and recommendations. We have used a similar approach successfully for previous research on safe medication use by Aboriginal people with mental health disorders [32], medication use by older Aboriginal women [24], consumer-driven projects [25, 45, 46] and other research [47-49].

### **Data collection**

Data was collected in 2001-2. Rich experiential data was collected through in-depth interviews and focus groups with consumers and service providers. Potential interview participants included adult Aboriginal people diagnosed with a mental health disorder, substance misuse or other culturally



determined social and emotional wellbeing problems, their carers or other adult family members, living in or near Port Lincoln. The Aboriginal research assistant contacted them and invited them to be interviewed for the project. He was in turn supported by his PLAHS social and emotional wellbeing team leader.

Health and welfare professionals, drug and alcohol workers, and other key service providers from Port Lincoln were interviewed also. The inclusion criteria for this group were that they provide professional health services or social support to Aboriginal people diagnosed with, or experiencing, a mental health (social and emotional wellbeing) disorder, their carers or other family members. Purposive and opportunistic sampling strategies were used to gain a range of voices and viewpoints.

One-to-one interviews or focus groups with up to six people were conducted by an Aboriginal research assistant or another member of the research team, following a semi-structured interview guide. These conversations were recorded on audiotape or in writing with informed consent of all participants. Participants were assured of confidentiality and anonymity, and could choose not to answer any question and withdraw consent at any time. The interviewer made notes (written and/or taped) to supplement the interviews.

A total of 14 clients, carers and workers participated in nine interviews and focus groups:

- Interview with a person with a mental health problem
- Interview with a person with a mental health problem
- Interview with a person with diagnosed mental illness and an alcohol problem
- Interview with a person who had a mental health problem in the past
- Interview with a carer of a person with complex health problems
- Interview with a social worker
- Interview with Social and Emotional Wellbeing worker
- Interview with an Aboriginal Health worker
- Focus group with six Aboriginal health workers from PLAHS

Tapes and handwritten notes were transcribed verbatim. Where possible, an Aboriginal member of the project team checked the accuracy of transcripts and assisted with local terminology and language.

## **Data analysis and development of recommendations**

Preliminary qualitative analysis of each interview and focus group transcript was conducted, based on the headings in the interview guide. Key information and quotes from interviews were coded under those headings

while reading and re-reading the transcripts and listening to the tapes. These were then categorised further into themes, based on the issues and concepts mentioned in the grant application and interview guide and others that emerged from the interviews. A short summary was then prepared for each transcript. Finally, all the findings were integrated into one document, to give an overall picture, highlighting common themes, key issues, similarities and differences. The analysis process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and as deeper analysis occurred [50]. Other researchers from the team cross-validated the analysis [51]. Preliminary findings were presented to steering committee members and key informants for further elaboration and validation. Notes from these meetings were included as data where appropriate. The steering committee in collaboration with the project team developed recommendations based on the interview findings. The researchers directly involved in the local project recorded their reflections and ideas emanating from interviews with key informants, focus groups and steering committee discussions, and these too were included as data.

Excerpts from interviews exactly as spoken by participants were included in the document to illustrate key points, and to demonstrate their credibility. To ensure that people and events could not be identified in the quotes, or for clarity, it was occasionally necessary to omit a few words (shown thus...) or substitute/add some words (in brackets).

Informed by the findings, recommendations for improving quality use of medications were developed collaboratively by the research team, steering committee, Aboriginal health workers, social and emotional wellbeing and substance misuse workers, and other key stakeholders. Where time and resources permitted, selected recommendations were implemented and evaluated as part of this project, and these are detailed below in 'Early outcomes and future plans'.

## **Findings**

All client/carer participants were women, aged mid-thirties or older, and Aboriginal. Three of these women had current diagnosed mental illness, and one of these also had an alcohol problem. Another 'client' participant had suffered a mental illness in the past but was now well. One woman cared for a family member with a longterm physical illness which impacted on his social and emotional wellbeing. Several of these participants also had chronic physical illnesses such as arthritis, thyroid deficiency and epilepsy. The health and community workers interviewed included non-Indigenous providers of a range of services and supports to Aboriginal people with mental health disorders and their families, and Aboriginal health workers from PLAHS.

Most client/carer participants had lived at the same address for several years, generally with their partner and children. Education level and employment history varied. One client had a disability pension, but it was not clear from the interviews whether the other client participants were currently in paid work, looking for work or receiving benefits, or if the mental illness impacted on their work or study options. The carer participant spoke of her ineligibility for a carer's allowance when working, and of the difficulties she faced paying the many bills associated with her relative's illnesses unless she worked. For example she had to pay for some medications, respite and ambulance cover.

Most client/carer participants used PLAHS. They felt at ease there, and more confident of understanding and respectful treatment from people who share their cultural background. They told of accessing counselling, social and emotional wellbeing services, drug and alcohol services, referrals to medical specialists, transport assistance and social outings via PLAHS. The various workers interviewed confirmed these views. PLAHS has links with general practitioners, the local hospital, community mental health team, consumer-driven mental health support groups eg Open Mind, police, prison, women's shelter, housing trust and other agencies [21, 52, 53]. These links were strengthened during the course of this research.

Aboriginal clients also made use of mainstream services, and named the hospital and local GPs, and community services like domiciliary care, Family and Youth Services (FAYS) and Options coordination. According to the steering committee, mainstream services available relevant to mental health in the Port Lincoln area include: Port Lincoln Health Services comprising the hospital and a number of community health centres, the Investigator clinic which now includes a psychiatrist, the Eyre regional mental health service, Drug and Alcohol Services Council outreach, Child and Adolescent Mental Health Service, FAYS, Centrelink, SA Housing Trust, numerous general practices, surgeons, visiting medical specialists, West Coast Community Services, Carers Association, Options Coordination. Most client/carer participants said they knew about most health and community services available in the area. However several participants observed that many people do not seek or find out about available services and assistance until their problems are very severe. PLAHS workers identified the need to pro-actively compile and disseminate essential information about Aboriginal and mainstream services.

Several participants voiced a desire for more Aboriginal services, eg:

*I'd like it if we could go to Aboriginal people, you know, because they understand where you're coming from, rather than going through the mainstream. Because like they've never sat and been broke or they've never sat and had family members die... because Aboriginal people are really close to each other, you know, and that's a hard thing to cope with. (PL#1)*

One participant was reluctant to use some mainstream health services because her relative was not always treated with dignity and cultural sensitivity. Workers also reported racist attitudes by some mainstream doctors which are consequently avoided by Aboriginal people:

*I don't think mutual respect is actually shown in this town. (PL#6)*

The local hospital was also criticised for institutional racism, which obviously impacts on access to culturally appropriate services.

*There's nothing in the hospital that would actually make an Aboriginal person feel comfortable in the environment there. (PL#7)*

It appeared that a small minority of Aboriginal people prefers not to use PLAHS. The worker participants suggested that some Aboriginal people might not use PLAHS due to confidentiality issues and therefore prefer to use the mainstream services instead. Another worker said that Aboriginal people who originally came from areas other than Port Lincoln may not use PLAHS due to perceived political reasons, but stressed that PLAHS made strenuous efforts to be inclusive in their service provision.

Several worker participants wanted a more integrated approach to social/health problems involving education, housing, early intervention in violence, family support, drug and alcohol services, mental health services, etc in Port Lincoln. This would require sharing of resources, being less territorial about which agency does what, and overarching management structures that prioritise the needs of individuals and families over the needs of organisations.

PLAHS has a social and emotional wellbeing team that provides drug and alcohol counselling, mental health, Bringing Them Home and family support services. The social and emotional wellbeing team works closely with the mainstream mental health team as well as GPs and visiting psychiatrists when possible, although this depends on individual (mainstream) worker commitment and attitude. However there is no formal liaison role, protocols or pathways of care between PLAHS and mainstream mental health services, nor with local GPs. It was reported that unless the social and emotional wellbeing team initiates contact, eg when a client is released from hospital or comes back from treatment in Adelaide, communication and streamlined service provision frequently breaks down. An example was given of a client who was released from psychiatric hospital care in Adelaide, without contacting family or health workers in Port Lincoln, and expected to manage his own medication, yet clearly being incapable, and with no arrangement for followup in the community.

The worker participants all expressed frustration at poor communication between services, particularly with metropolitan organisations. Consequently continuity of care and appropriate pathways to support

vulnerable clients is lacking, eg for those detained or voluntarily admitted to psychiatric care in Adelaide. For example the social and emotional wellbeing team who know the client, their family and context best are rarely consulted by metropolitan hospitals nor informed of their release, which clearly impacts on the quality of service and support they can provide. There is no detox or sobering-up facility, and no residential mental health hospital care available in Port Lincoln, and clients needing such treatment must leave town. Participants wanted more mental health services in Port Lincoln, such as a dry-out centre in which people could support their peers to overcome addiction, and a residential mental health facility. Workers and clients alike stressed the need for family support and a non-clinical environment, eg:

*I'd like to see a centre where, where people with mental health problems could be treated. Uh, not necessarily up at the hospital but maybe in a more better surrounding, ya know, like? And um, even have something handy in town ... like a little village or something ... So that helpers, you know like parents an' that can just come in it an' see everyone you know... 'cause there's so much stigma. (PL#4)*

The health and community worker participants were unanimous in their desire for basic medication, drug and alcohol, and mental health training. Workshops and other strategies, eg support groups, to increase community awareness about mental health problems and reduce shame and stigma were also called for:

*We do have two consumer groups: there's Open Mind and STEPS, and there is also a carer's group here too, um, and I think there's maybe Aboriginal carers have been involved with the carer's group. I don't know if there are any Aboriginal people involved in Open Mind and STEPS.... A couple of our workers are meant to be you know, um, taking part in those groups too, but it's just time I think more than anything else, doesn't do it. (PL#9)*

The focus group of Aboriginal health workers agreed that the social and emotional wellbeing team is under enormous stress, constantly negotiating with families and services, and trying to do the best for everyone. Aboriginal health workers also have their own mental health problems and major family problems to deal with, and strategies for mutual support have been developed:

*So yeah, our mental health is probably something which we recognise we have to look after and we do that pretty well in supporting each other and we structure in a day of perhaps once every 3 months where we actually go out to the national park and just have, just like a, breather day or something. (PL#7)*

It was reported that some families have unrealistic expectations that the social and emotional wellbeing team can and should address all their problems. It was suggested that workshops for community members should

include sessions to clarify caring responsibilities and roles of families and how they can work together with Aboriginal health workers.

Client/carer participants told how they felt ashamed and embarrassed about not coping with their mental health problems and how they appreciated having someone to talk to. PLAHS was praised for its sympathetic and welcoming manner, eg:

*I know myself that if I get really bad I can just walk in there and sit down and have a coffee and, and I think that's a big plus er in the, in the community, yeah. (PL#4).*

However, participants recognised that many Aboriginal people needed counselling for a range of social and emotional wellbeing issues, and needed encouragement to seek timely help, as in these examples from the interviews.

*I think there's a lot of people out there, you know my own people that they really need support and just someone to talk to, you know. (PL#4)*  
*Don't leave it too late to seek help. Don't be afraid of what others will say. Don't take the blame. Talk about it. (PL#2)*

Participants felt that Aboriginal and non-Aboriginal health and community workers need more training in how to cope with crisis situations, especially for young people at risk, including how to talk to them, settle them, assess them, and manage them in creative and effective ways.

Views about mental health varied, depending on the experiences of the participants. The worker participants agreed that poor social and emotional wellbeing is related to oppression due to racist policies of the past and present.

*It's so complex. ...Just the inter-generational trauma. The grief and loss of disconnection with land and families and... not having a sense of belonging anywhere. It's all that disconnection stuff and lack of self esteem. Lack of identity ... and it's a current or contemporary discrimination practices too and that. (PL#7)*

Depression and substance misuse were considered common and major mental health problems in the Port Lincoln Aboriginal communities. Most worker participants felt that Aboriginal people, like non-Indigenous people, generally have stereotypical views about mental illness, and there is shame and stigma associated with it. In contrast one Aboriginal health worker thought that depression was so commonplace that it was scarcely remarked upon and not viewed negatively at all.

Clients and carers understood that there are different types of mental health problems that help is available and that some mental illness can be treated with medication. Most client/carer participants coped well with their mental

health problems, taking medication as prescribed and seeking counselling or other help when necessary. Clients with stable mental health disorders who were well supported and had a consistent medication regime were generally satisfied with their treatment. Those who were still finding the appropriate treatment were less satisfied, but most acknowledged that medications could be helpful:

*Well once the medication has set in ... everything's on a straight level. (PL#3).*

However, some worker participants felt that clients often had difficulty accepting that they had a mental illness and needed medication. It was suggested that patients and carers need education about the benefits of medication for certain mental health disorders. This was particularly important where problems were so severe that treatment orders were required. Resentment about treatment orders often led to difficulty re-establishing good rapport between workers and clients.

Negative effects of medication were also discussed. Unpleasant side effects were a major deterrent to compliance.

*Yeah well they just say it's the side effects and you have to wait until it sets in. And by the time that I am supposed to have (to) wait until it sets in, ... my body's all yuck and I feel yuck and I just want to push them aside. (PL#3).*

The worker participants agreed with this view, and though they admitted limitations in their knowledge about medications, believed they could identify problems and refer appropriately.

*We usually rely on working with the doctors who are responsible for the mental health team. Just to clarify what they're meant to be taking. We monitor that I guess because we monitor their well being. So we're pretty clued up in terms of what side effects could be like slurred speech or the shuffling feet or the dribbling stuff or just the non-focus. (PL#7).*

Most clients were confident about talking to their doctors about side effects, but it was suggested that some people should be more assertive about this:

*I think a lot of people... probably do take medication that does upset them where they should stand up and say you know, that is not agreeing with me and change it. (PL#4)*

Similarly the workers felt that doctors should take more responsibility for ensuring that their patients medication s were adjusted to individual need:

*Doctors can, you know, probably spend more time with them working out what is right and what is the best stuff. You know I believe doctors could probably do a lot more in making sure that the medication is the right medication and the dosage is right. (PL#8).*

Another participant had suffered depression and range of stress-related physical symptoms. She was prescribed antidepressant and other medications, but her health did not improve. She felt that the medications were making her even more unwell and described her life at the time as joyless and robotic:

*Yes, I did have mental health problems. It was to do with my personal life and the way that I handled my personal life was to go within myself and I became very depressed. They had tried me on various medications. At one stage in between the time that they take to wean you off one medication to try another one, I had suicidal thoughts. Nothing became of it. (PL#2)*

She realised that she needed to make a change in her life and take control to overcome her depression. She weaned herself off the medications and changed her life, despite lack of family support. For this participant, medication did more harm than good, and addressing the root cause of her depression led to recovery.

*I found strength that I didn't know I had enabled me to confront my problems head on and to change them. (PL#2)*

A carer told of the frustration and sense of failure felt by her relative, because his illness prevented him from fulfilling his traditional responsibilities to his family and community. This situation caused him great social and emotional distress. She told of the mental strain she felt as carer, and of the lack of support for her role. This participant also told of the effects on her relative of the strong painkillers (MS Contin, Panadeine Forte) that he took for his condition, such as nightmares and isolation, and how he became moody and irritable when unable to get them for some reason (it was unclear from the transcript why he couldn't get them). From the interview it appears that health professionals may not have formally considered the social and emotional wellbeing of both carer and client in this case. The worker participants also agreed about the enormous burden that carers of people with mental health problems carry, and their need for support and respite.

The client/carers participants generally used prescribed medications safely, and most felt they had as much information as they needed about the medicines and the conditions for which they were prescribed. They followed doctors' instructions about dosage and frequency, stored them out of reach of children, disposed of damaged or out-of-date medicines appropriately and did not share medicines with others. All were responsible for obtaining and administering their own medicines, and none were on treatment orders. The carer was concerned about having dangerous drugs in the house where children might find them, but her strategies for safekeeping were not explored.



In contrast the worker participants believed that many Aboriginal people have poor knowledge or are not well informed about their medications compared to non-Indigenous clients. They reported that clients were confused about names of medications, what they are for, how they affect the body, how effects may vary dramatically with the dose, etc. The worker participants also said that most Aboriginal people are generally compliant with medications if there are no problems, will not question doctors, are scared of doctors, and will not go back to them and say that medications are not suiting them but instead just stop taking them. Numerous anecdotes were told of clients ceasing medication due to unpleasant side effects, or not even taking medications due to fear of side effects, without questioning their doctors. Only one worker said that indiscriminate use of medications occurs, eg sharing of medications.

According to the worker participants, most of the doctors in Port Lincoln don't explain mental illness and medications very well:

*I'm sure that er the GPs speak way above um most people, most people's head and um particularly people with mental illness, um, um I always find that though person accepting their illness tends to be er the biggest obstacle. (PL#9)*

However the two doctors at PLAHS were praised for their communication skills:

*I know the two doctors that we have in our clinic explain very well, but they, they cooperate with Aboriginal people very well and they, they even draw pictures so that you can understand what's going on, so I know just in our little health service here we have two doctors that are excellent with Aboriginal people. (PL#9)*

One participant was annoyed about being "used as a guinea pig" (PL#5) during a drug trial, but the circumstances were not clarified. This person also believed that cheaper, subsidised brands of medication are sometimes of inferior quality. It seems from the worker interviews that few clients understood that it takes time and testing to find an appropriate drug and dosage to suit each individual.

Cost of medications was not a problem for most client/carer participants. The worker participants agreed that cost of medications did not usually determine whether medications were taken or not, but that denial of need or side effects were more likely to limit compliance. Workers reported that some clients had good relationships with local pharmacists regarding payment for prescribed medication, but that other pharmacists would not fill prescriptions unless they could be collected and paid for on the day. There is no pharmacy at the local hospital or PLAHS. Involvement in the project has facilitated links between PLAHS and the senior pharmacists to investigate possible ways of addressing this issue, eg by keeping a limited pharmacy supplies at PLAHS.

Several people said they would like the opportunity to try traditional medicines or consult Ngangkari. One participant believed that Aboriginal people need special and different medicines:

*I don't believe in it (white man's medicine), but that's my belief, that our body structure's different...And um you know they are treating us like white people which is wrong. (PL#4)*

Interestingly the Aboriginal Health Workers did not know of any systems or funds for bringing in recognised traditional Aboriginal healing practitioners.

Some client participants admitted going without their prescribed medications on rare occasions, but reasons were not explored. One client reported that small problems magnified into big issues and that she lost her temper more easily if she stopped taking her medication. Side effects of medication were a major problem to compliance (discussed above), and included feeling drained, feeling like a zombie, poor balance, shuffling, dribbling, breast changes, weight change and feeling sick.

Client/carer participants knew that mixing prescribed medicines with alcohol or other illicit drugs is dangerous:

*When I'm on medication I can't drink full stop. It doesn't mix. (PL#3).*

Most client participants did not drink or smoke marijuana except on rare occasions. One participant struggled with alcohol addiction, but she avoided alcohol when taking medication for her mental health disorder.

*I know I've got a sort of addiction. You know if I go to have one I want another one and another one and another one...It's really hard to escape you know ... when there's a household of people and pay days are at different days. ...I'm more or less a bender drinker if I'm not on medication. (PL#4)*

The worker participants spoke at length about drug and alcohol problems in Port Lincoln, among Aboriginal and non-Aboriginal people, particularly youth. Some directly associated substance misuse with mental illness including paranoia, psychosis and depression. Others saw substance misuse as symptomatic of social and emotional distress. Workers requested more information about coexisting addiction and mental health problems. Alcohol and marijuana were reported as the most commonly used drugs among Port Lincoln Aboriginal people, although amphetamines, improper use of prescribed drugs, solvents and injecting drugs were also mentioned. Easy access to alcohol by minors was seen as a big problem. Workers expressed grave concern about lack of appropriate local facilities to help people struggling with substance misuse problems such as intoxication and addictions, particularly among adolescents, and their families.

## Discussion and recommendations

This project explored issues, contexts and needs impacting on safe medication management by Aboriginal people with mental health problems and their carers in the Port Lincoln region. The findings fall into the following broad themes, all of which affect use and management of medication, directly or indirectly:

- Poverty and unemployment
- Need for accessible, affordable and culturally appropriate mental health services
- Confidentiality and inclusiveness
- Coordination of services and integrated pathways of care for Aboriginal people
- Education
- Carer support
- Support for the PLAHS social and emotional wellbeing team
- Information and support for safe medication use

Interestingly, similar issues were uncovered in our pilot study [32], and in our research in other parts of South Australia and from a SA-wide survey of health professionals (all undertaken as components of the SA-wide research project of which this research is a part, and to be reported separately in 2003). This consistency of findings from different areas, and with use of multiple qualitative and quantitative research methods, indicates the credibility of the results and demonstrates the trustworthiness and validity of the research approach.

The research team and the Port Lincoln steering committee discussed the issues revealed by the data, and collaboratively developed the report and recommendations. It is clear that many of these issues are fundamental to Aboriginal well being, and will only be addressed through sustained commitment of resources and energy. However there are a number of key issues relevant to medication management for Aboriginal mental health which could be solved through creative redirection of resources/personnel, modifications to policy and practice, collaboration, better integration of services, targeted education and training, and lobbying for, and accessing, additional funds.

It is notable that although many of these issues and recommendations have been identified previously and reported widely, and national and regional strategies and implementation plans have been formulated [7-12], there has been little evidence of improvement in living standards, mental health and quality use of medication for Aboriginal people. This is a major concern.

## **Poverty and unemployment**

Entrenched poverty and unemployment impact on the social and emotional wellbeing of Aboriginal people wherever they live. This is relevant to quality use of medicines because social and emotional distress is associated with increased use and misuse of prescribed and non-prescribed medications, alcohol and other drugs.

The need for more employment opportunities for Aboriginal people in mainstream health and community services and private enterprise was a consistent theme that emerged from the project's interviews and focus groups, not only in Port Lincoln, but also in other urban and rural areas across SA. It was agreed that more Aboriginal staff were needed generally, in the Aboriginal services sector as well as mainstream services and businesses, eg health workers, police, nurses, doctors, teachers, social workers, welfare workers, DHS staff, shop and bank staff. It was also recognised that although many Aboriginal people have successfully completed training in a wide range of areas, there are few opportunities for satisfactory work and career paths locally. For example, the steering committee estimated that there are currently 20 Aboriginal teachers and more than 5 Aboriginal nurses in the Port Lincoln and Eyre Peninsula area who are not working at present.

### **Recommendations**

1. Lobby government policy makers and private enterprise to develop strategies to recruit and retain Aboriginal workers into local services and businesses.
2. Assist Aboriginal people to build their confidence and skills in career development and gaining employment.

## **Need for accessible, affordable and culturally appropriate mental health services**

Another underlying theme was the need for improved and appropriate service provision in local and metropolitan mainstream mental health care sectors that reflects cultural awareness and respect, eg among staff of the local hospital and health services, as well as community and social services (including Centrelink) that Aboriginal people with mental health problems interact with. It is difficult for Aboriginal people with diagnosed mental health disorders or other social and emotional wellbeing problems, and their carers and family members, to achieve and maintain safe and effective use of medicines without support from professional services that are culturally respectful and understanding of the complex issues impacting on Aboriginal mental health.

### Recommendations

3. Introduce cultural awareness education at undergraduate level for doctors, nurses, health workers, and social services workers, and reinforce through regular in-service training and professional development.
4. Ensure Aboriginal representation on relevant curriculum boards.
5. Arrange placements/secondments for a range of workers from mainstream services and work experience placements for students in Aboriginal services eg PLAHS, and to gain experience and cross-cultural understanding.
6. Include cultural awareness and culturally appropriate practice criteria in selection and performance appraisal processes for the health and community workforce.

The findings also show that Port Lincoln and the Eyre region has inadequate special services to cater for the particular needs of people with mental health disorders (including drug and alcohol problems) and their families/carers, especially in crisis situations, confirming previously identified service gaps in the region [8]. The whole community (Aboriginal and non-Aboriginal) needs to work together to lobby for these services. Family and carer support is crucial, highlighting the need for these special services locally. In addition, Aboriginal health services should be fully involved in strategic planning and review of mental health services for the Eyre region. It is evident that appropriate, adequate and accessible mental health services are needed to ensure that Aboriginal people with mental health problems are provided with information and support to use and manage their medications safely.

### Recommendations

7. Ensure that Aboriginal health services and the communities they serve are fully involved in strategic planning and review of mental health services at State and Regional levels.
8. Lobby for the establishment in Port Lincoln of special services including alcohol/drug detoxification unit, alcohol/drug rehabilitation service, sobering-up unit, residential mental health facility, respite care, safe women's house, safe men's house, accessible and user friendly needle/syringe exchange, and mobile assistance/night patrol service.
9. Establish a supported accommodation 'village' for Aboriginal people with mental health problems and their carers, with supervision from the Port Lincoln hospital and/or PLAHS social and emotional wellbeing team.

## Confidentiality and inclusiveness

Several participants expressed concern about confidentiality at health and community services in Port Lincoln. This has been a consistent finding of

this project across SA, particularly in small communities where clients and staff know each other socially or are related. It is recognised that having Aboriginal staff is not enough to ensure quality service provision to all Aboriginal clients. Family or kinship ties may limit clients' willingness to divulge sensitive information or seek help. On the other hand, the diversity of Aboriginal peoples currently living in and around Port Lincoln, means that providing culturally appropriate service to everyone is especially challenging.

PLAHS is an Aboriginal community-controlled organisation and is mindful of these issues and potential conflicts. The Board of Management of PLAHS comprises a wide range of Aboriginal people reflecting the diversity of its clients, and PLAHS strives to provide quality services to all Aboriginal people in and around Port Lincoln. Aboriginal people with mental health disorders will be more likely to seek help for a range of issues, including medication management, from organisations that are committed to confidentiality and inclusiveness.

#### Recommendations

10. Prepare short plain language statements in a range of formats reaffirming the commitment of PLAHS and other organisations to confidential and inclusive service for all Aboriginal people, processes to achieve this, and grievance procedures. Suggested formats include posters, leaflets, fridge magnets, articles in local newspapers and newsletters, and local radio items.
11. Develop local mechanisms to ensure that Aboriginal people who choose not to use PLAHS are not disadvantaged, eg through limited access to resources and assistance. This may also require high-level policy modification so that funding goes with the client, rather than service.

### **Coordination of services and integrated pathways of care**

Better integration of health, community and social services was a major theme arising from the project in Port Lincoln and elsewhere in SA. This has been recognised in recent years at State and local level [12, 19, 20, 22, 23], and although there has been considerable progress in developing coordinated systems of care in Aboriginal communities [11], there are still many examples of poorly integrated service provision for Aboriginal people with mental health disorders. In particular, the findings highlighted the need for improved communication between local or metropolitan acute health services and PLAHS to achieve a continuum of mental health care, which includes attention to medication management.

#### Recommendations

12. Identify and build on existing systems of coordinated Aboriginal mental health care that work well.
13. Adopt an integrated regional approach to mental health service delivery, which involves the Port Lincoln Hospital, GPs, PLAHS, Port Lincoln adult mental health team, Port Lincoln Child and Adolescent Mental Health Service, and other local community and social services.
14. Develop protocols and clear pathways for Aboriginal mental health care and medication management collaboratively with all relevant services.
15. Identify key liaison people in metropolitan mental health services to communicate effectively with local caseworkers and carers in Port Lincoln, using clear protocols. These liaison people need to be located in Rural/Remote mental health service at DHS, Lyell McEwin Hospital, Flinders Medical Centre, Glenside, Royal Adelaide Hospital, Queen Elizabeth Hospital, Women's and Children's Hospital, prisons, parole boards, etc.

## Education

The need for more education and training for Aboriginal health workers and others was another major theme. It was recognised that all Aboriginal health workers and counsellors need to acquire generic and specialised skills that encompass mental health (social and emotional wellbeing), alcohol and drug use issues, and safe medication management, as part of 'everyday' practice, because they are required to deal with these common, diverse and complex health problems, often with limited backup support. Such education and training for Aboriginal health workers and other professionals is urgently needed to equip them to respond effectively to client and carer/family needs. Provision of training will require support from organisational leaders, dedicated resources and commitment to continuous quality improvement. Training should articulate with formal education pathways within VET and tertiary education sectors, with mechanisms for recognition of prior learning and credit transfer, to facilitate career progression and as an incentive to take part. Recommendations for professional training are listed below (training around cultural awareness is addressed above).

#### Recommendations

16. Provide mandatory accredited training for all health and human service workers, and carers, on Aboriginal mental health and medication management.
17. Provide education for health and community workers on drug and alcohol, mental health and substance misuse comorbidity, mental health and physical disease comorbidity, safe use of medicines, and crisis care.
18. Provide training on how to care for intoxicated people safely.

Education at community level, to increase understanding of mental illness and issues impacting on social and emotional wellbeing is needed. Strategies might include: building on existing initiatives of the national mental health strategy [54] in local schools and other community venues, holding an open day to showcase the work of the PLAHS social and emotional wellbeing team and the Port Lincoln mental health team, providing positive success stories to local media, continuing to talk openly about drug and alcohol issues and where to seek help.

#### Recommendation

19. Develop and implement a range of strategies to raise community awareness about mental health, and the range of services and supports available, to reduce the associated shame and stigma.

### **Carer support**

Caring for a person with mental health problems is exhausting, stressful and expensive. In Aboriginal families, carers are generally family members, often older women, who may be unwell themselves. When carers need to go to hospital for their own health problems, alternative and appropriate care arrangements for the person they care for must be made, and when discharged from hospital their carer obligations must be considered. Currently there are no funds allocated specifically for this purpose.

#### Recommendation

20. Lobby for funding specifically for respite care for Aboriginal people with mental health problems.

This project revealed that some carers in Port Lincoln lacked information about their rights and the availability of allowances and resources. They wanted to know more about mental health and medication use in everyday and emergency situations. In particular they wanted a better understanding of legal issues around treatment orders and the role of the Guardianship Board. Some carers were concerned about payback from family for unpopular decisions eg those relating to treatment orders. It was revealed also that currently available support for carers in Port Lincoln was not always culturally appropriate, and that there was a reticence among Aboriginal people to access organisations such as the Eyre Peninsula Carers Association. The steering committee recognised the potential for carers to share their knowledge and experiences to improve support services.

#### Recommendations

21. Inform Aboriginal carers about their rights and how to get practical assistance, eg self help groups, help with medication management, crisis care, treatment orders, drug and alcohol services.



22. Promote the support, information, expertise, advocacy and resources of key services for Aboriginal carers and clients eg Eyre Peninsula Carers Association.
23. Ensure that mainstream services that interact with Aboriginal carers, eg Home and Community Care (HACC), Options Coordination, Domiciliary Care and Department of Human Services (DHS), are more accountable to carers through appropriate leadership, staff support and staff training.

## **Support for the social and emotional wellbeing team**

The social and emotional wellbeing team at PLAHS supports Aboriginal people with mental health (social and emotional wellbeing) problems, including drug and alcohol, and their carers/families in the Port Lincoln area. It was revealed that social and emotional wellbeing team members are overburdened and stressed, and have dual responsibilities as professionals and as Aboriginal community members. The team already uses some strategies to help cope with their demanding roles, eg regular outings, 'time out' when needed, peer support and debriefing, but more support for this key group is needed. External mentors and counsellors were suggested.

### **Recommendations**

24. Build on existing strategies to support the social and emotional wellbeing team at PLAHS, eg debriefing, peer support.
25. Develop an external mentor system to support the social and emotional wellbeing team at PLAHS
26. Use a system for staff to access external people for confidential stress counselling, eg Employee Assistance Program

## **Information and support for safe medication use**

The data clearly showed that there is a need for specific information, resources and service delivery arrangements to support safe use of medicines. It was agreed that finding ways to ensure that Aboriginal clients with diagnosed mental health disorders fill their prescriptions and take their medicines was of paramount importance. Fear of prescribed medicines, not accepting diagnoses of mental health disorder, not understanding the potential benefits of medicines for diagnosed mental health disorders, confusion about the need for regular medication for concurrent health problems such as diabetes or renal disease, reluctance to question doctors or pharmacists about side effects, poor compliance, lack of money for medicines, not prioritising health and medication issues compared to other issues, and many other factors and life contexts impacted on medication use and management. Many of the education, coordinated care, and culturally appropriate service delivery strategies already outlined above would have an

indirect impact on safe use of medicines. Establishing systems and protocols that enable easier access to medications, and ways of monitoring medication management, would have a more direct impact on safe medication use. This would require collaborative efforts by PLAHS, pharmacists, GPs, RNs and the local hospital, and draw on primary health care principles.

#### Recommendations

27. Establish systems to improve access to medicines for certain clients.
28. Establish more effective systems for monitoring and supporting medication use and management.

## Early outcomes and future plans

A major success of this project has been the development of an excellent and ongoing relationship between the research team, PLAHS and other health service providers in Port Lincoln. This relationship is thoroughly grounded in earned trust, mutual understanding of goals and priorities, respect for our different but complementary knowledge and skills, and the sustained commitment of all parties to improvement in Aboriginal health. It has taken considerable time, many visits, continued discussion, advocacy, and shared decision-making between everyone involved to achieve conciliation. These efforts have been worthwhile, not only in achieving the aims of this project, but also in building the workforce capacity in Port Lincoln, and further collaboration in training and research to benefit Aboriginal people in the region. These are described below (see “early responses to recommendations”).

When PLAHS was first invited to participate in the project, its Board of Management had many questions and concerns, eg about confidentiality and ownership of data, and ethical research practice. In response to these important issues, an acceptable protocol for secure and ethical handling of confidential data was developed collaboratively by the research team and PLAHS, and applied throughout this SA-wide research program. The protocol is being seen as the ‘gold standard’ for all Aboriginal research among colleagues. Another mechanism for building good collaboration was the establishment of the Port Lincoln project steering committee to guide the project locally, and representation of the Director of PLAHS, Ms Jackie Ah Kit, on the Statewide steering committee.

The PLAHS Board of Management rightly wanted any research to lead to sustained benefit to the Port Lincoln Aboriginal community. They were also concerned about the impact on workload in an already overstretched health service, competing priorities at PLAHS, and the burden of research on a small community. After several presentations to the Board by members of the

research team, it was established and understood by all that the project included implementation of research findings into practice. Demonstration by the researchers of their willingness to put the needs of the community above the needs of the research project at all times was pivotal to achieving a trusting relationship. For example, a workshop “Responding to Needs” was held in direct response to issues identified very early in the project, and led to better links between Aboriginal and mainstream health and social services, and immediate benefit to Aboriginal clients and staff. On the other hand, the willingness of PLAHS staff to acknowledge problems uncovered during the research, enabled creative responses to these issues.

## **Early responses to recommendations**

In direct response to the findings and recommendations of the project in the Port Lincoln region and elsewhere in SA, there have been several initiatives, as described below.

Response to Recommendation 3 (Introduce cultural awareness education at undergraduate level for doctors, nurses, health workers, and social services workers, and reinforce through regular in-service training and professional development).

The pilot study for this project [32] revealed that the Adelaide Indigenous health workers in partnership with Northern Division of General Practice had developed ways of improving cultural awareness and communication skills of GPs [55]. Also, examples of institutional racism were highlighted in the Coober Pedy component of this SA-wide project, and in response to this issue the research team conducted a workshop on cultural safety for health professionals and provided procedure manuals outlining duty of care and legal obligations. There is the potential to build on these innovative teaching and learning strategies in the Port Lincoln region and elsewhere, and with a range of health and other professionals.

Response to recommendation 8 (Lobby for the establishment in Port Lincoln of special services including alcohol/drug detoxification unit, alcohol/drug rehabilitation service, sobering-up unit, residential mental health facility, respite care, safe women's house, safe men's house, accessible and user friendly needle/syringe exchange, and mobile assistance/night patrol service).

Independently of this research, a project officer was employed to identify such needs in the Port Lincoln area, and write a substance misuse plan for the area.

Response to recommendation 10 (Prepare short plain language statements in a range of formats reaffirming the commitment of PLAHS and other organisations to confidential and inclusive service for all Aboriginal people, processes to achieve this, and grievance procedures. Suggested formats

include posters, leaflets, fridge magnets, articles in local newspapers and newsletters, and local radio items).

PLAHS staff members brainstormed ideas to promote PLAHS' commitment to confidential and inclusive service for all Aboriginal people, setting an example for other service providers in the region. PLAHS workers identified the need to pro-actively promote comprehensive and appropriate information about not only Aboriginal services such as PLAHS, but also mainstream services.

Response to recommendation 14 (Develop protocols and clear pathways for Aboriginal mental health care and medication management collaboratively with all relevant services).

As part of this SA-wide project, the research team is negotiating with the Eyre Peninsula Division of General Practice, PLAHS and Mental Health Services in Adelaide to develop and evaluate protocols and processes for coordinated Aboriginal mental health care and safe medication management. Seeding funds have been obtained from the Flinders Institute of Health Research to conduct this work which builds on previous and current work on coordinated systems of care and chronic disease self management in Eyre district and elsewhere [11]. This project recommendation has also influenced the decision for the SA Department of Human Services to provide substantial additional funding for health services in the Port Lincoln region.

Response to recommendation 16 (Provide mandatory accredited training for all health and human service workers, and carers, on Aboriginal mental health and medication management).

This project found that there was an urgent need for such training, not only in Port Lincoln, but also across SA. In response to this identified need and as part of the research project, members of the research team ran an intensive 3 day course on safe medication management for Aboriginal mental health in Adelaide in September/October 2002 through the School of Nursing & Midwifery at Flinders University. This course was designed for a variety of workers including Aboriginal health workers, drivers, substance misuse workers, and mental health workers, all of whom need to know how to safely transport, handle or otherwise manage medications. Four workers from Port Lincoln attended. Formal evaluations indicated that the course increased participants' knowledge and understanding of key concepts related to social and emotional wellbeing, medications for mental health, drug/alcohol problems, how medicines work, safe management of medicines, legal issues, and rights and responsibilities of clients and workers (all  $P < 0.01$ , comparing pre and post course self-report scores). Another positive benefit was the increased sense of worth that workers, particularly the drivers, felt when they understood the importance and responsibilities of their roles. The course is being held again in February 2003 in Adelaide. All participants received a certificate enabling articulation with other courses and career

development. As a result of this project, and from the positive feedback about the course, PLAHS would like all its workers to receive such training. Therefore members of the research team in collaboration with PLAHS have applied for funding through RHSET to provide this training course at Aboriginal Health Services across the Eyre region, and to develop and provide guidelines and protocols for handling medicines safely. By bringing the course and materials to the workers, attendance and usefulness will be optimised.

Response to recommendation 17 (Provide education for health and community workers on drug and alcohol, mental health and substance misuse comorbidity, mental health and physical disease comorbidity, safe use of medicines, and crisis care).

Information about these issues was provided to a range of workers at a workshop “Responding to needs” held as part the project in Port Lincoln in February 2002. The workshop participants requested further training, and so a 3-day alcohol/drug and mental health comorbidity course was held in Adelaide in May 2002, and in Port Lincoln in June 2002. The course was developed, implemented and accredited as a multidisciplinary postgraduate topic by the Flinders University School of Nursing and Midwifery. The course is also recognised formally through a Memorandum of Understanding with the Spencer Institute of TAFE for those eligible for entry into vocational education programs. PLAHS hosted the first course in the Eyre region in June 2002. The 17 participants included Aboriginal health workers, mental health workers, hospital based registered nurses/postgraduate mental health students, social workers and other professionals, both Aboriginal and non-Aboriginal, mostly from Port Lincoln. An expert clinical team from Flinders University, Flinders Medical Centre, Drug and Alcohol Services Council, SA Mental Health Services and local Aboriginal PLAHS personnel delivered this program. Innovations included videoconferencing and participation of local service providers in teaching. Evaluation forms were distributed immediately after the course, and results analysed. Participants found the course to be informative, well presented and relevant to their work. Participating in the course improved self-reported understanding of the key issues relevant to Aboriginal people with mental health and drug/alcohol problems significantly ( $P < 0.05$ , comparing pre and post course self-report scores).

Response to recommendation 18 (Provide training on how to care for intoxicated people safely).

This training need was identified as needed by substance misuse workers and other participants in this project, and therefore a 3-day intensive course on assessing and caring for intoxicated people safely was presented by the Flinders University School of Nursing & Midwifery under the coordination and guidance of the chief investigator, in May-June 2002 at Port Augusta. Two health workers from PLAHS attended. The program included the DHS-

accredited clean needle and syringe course. The course was very well received and a formal evaluation on completion indicated that participants had gained better understanding of how to practice safely in these high risk workplaces, and accurate information to pass on to their clients.

Response to recommendation 19 (Develop and implement a range of strategies to raise community awareness about mental health, and the range of services and supports available, to reduce the associated shame and stigma). As an extension of this project, members of the research team in collaboration with PLAHS are seeking funding for community and workforce education programs on the topic.

Response to recommendation 21 (Inform Aboriginal carers about their rights and how to get practical assistance, eg self help groups, help with medication management, crisis care, treatment orders, drug and alcohol services).

As a direct result of this project, key staff from PLAHS and other local health and community services who work with carers/families of Aboriginal people with mental health problems have a better understanding of these issues and can inform carers. These workers attended a workshop “Responding to needs” which was held as part of the project’s activities in Port Lincoln during February 2002. The workshop included a videoconference with the SA Guardianship Board that clarified its role and function in assisting people with mental health problems, and in particular treatment orders for medication [56, 57]. PLAHS is exploring ways for carers to request and access safe, timely and confidential help from the Guardianship Board when a repeat treatment order is necessary, as this is distressing for all concerned and because carers may fear payback from the client or other family members. This might involve delegation of day-to-day clinical management from the allocated psychiatrist (generally in metropolitan Adelaide) to the regional mental health team who have agreed to work with families and PLAHS workers to address this problem. Our planned new research on coordinated Aboriginal mental health care (discussed above in relation to response to recommendation 14) will also consider these issues.

Response to recommendation 22 (Promote the support, information, expertise, advocacy and resources of key services for Aboriginal carers eg Eyre Peninsula Carers Association).

This group has monthly gatherings in the region, and 20% of its members care for someone with a mental health problem. The association keeps a database which informs HACC and other service providers about the needs of its members. The Eyre Peninsula Carers Association comprises mostly non-Aboriginal people, but members are non-judgmental, and include carers of people with all sorts of problems (mental illness, drug and alcohol problems, physical disabilities). They organise an annual two-day retreat for

carers. As a result of this project the coordinator is working with PLAHS to promote the organisation and encourage Aboriginal carers to join and benefit from its expertise and resources. Also, discussions are underway regarding possible new collaborative projects with the manager of the Adelaide Central Mission Training Unit, which is a major provider of respite and carer services in the Eyre Peninsula region.

Response to recommendation 26 (Use a system for staff to access external people for confidential stress counselling, eg Employee Assistance Program). Following a specific request from PLAHS, the chief investigator has provided information about drug and alcohol use in nursing workplaces [58], and will assist PLAHS in addressing these issues. PLAHS is also exploring options for assistance through local Employee Assistance Programs.

Response to recommendation 27 (Establish systems to improve access to medicines for certain clients).

The project team consulted with Amanda Sanburg, Pharmacist from Port Augusta Hospital, who has reviewed and advised on pharmacy needs and services for northern SA Aboriginal communities [38]. PLAHS cannot provide prescribed medicines under S100 legislation, because there are pharmacies close by and Port Lincoln is not remote. Similarly, providing prescribed items at PLAHS is not possible without a pharmacist on staff. PLAHS could arrange with a local pharmacy to hold a limited imprest of non-prescription items, eg for treatment of fever, skin infections, head lice, but PLAHS would need to pay the full amount for these items. An alternative idea that PLAHS might consider is to subsidise the costs of medicines dispensed at nearby pharmacies for certain clients who might not obtain and take their medicines otherwise. There is already a similar arrangement in Port Augusta, where for certain clients, the GP marks the prescription with a 'red dot' sticker that indicates to the prescribing pharmacist that the Aboriginal health service will subsidise the cost, encouraging patients to fill their prescriptions.

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## Appendix 1.

### Port Lincoln Steering committee

Ms Lucy Adadiez	Manager, Family and Youth Services, Port Lincoln
Ms Jackie Ah Kit	Director, Port Lincoln Aboriginal Health Service
Mr Simon Boyce	Case Manager, Regional Mental Health Services
Mr Garry Burgoyne	Social Health Worker, Port Lincoln Aboriginal Health Service and Aboriginal Research Assistant for this project
Mr Peter Burgoyne	CEO, Port Lincoln Aboriginal Community Council Inc
Dr Neville Carlier	Medical Practitioner, Investigator Clinic
Mr Robert Dann	Port Lincoln Aboriginal Health Service
Mr Haydn Davey	Chairperson, Port Lincoln Aboriginal Community Council Inc.
Ms Megan De Witt	Co-ordinator, Port Lincoln Aboriginal Community Council Inc
Ms Vicki Gould	Social and Emotional Wellbeing Counsellor, Port Lincoln Aboriginal Health Service
Mr Les Kropinyeri	Chairperson, Port Lincoln Aboriginal Health Service
Mr Frank Laughton	Substance Misuse Worker, Port Lincoln Aboriginal Health Service
Ms Sarah Lindsay	Female Substance Misuse Worker, Port Lincoln Aboriginal Health Service
Mrs Glenda Millard	Port Lincoln Carers' Association
Dr David Mills	Medical Practitioner, Investigator Clinic
Dr Christine Lucas	Medical Practitioner, Investigator Clinic
Ms Vivian Ridgeway	Social Worker, CAMHS
Mr Andy Schutz	Principal Pharmacist, Schutz, Bassham and Sampson Chemists
Mr Michael Wallis	Co-ordinator, Regional Mental Health Services
Mr Allan Wilson	Chairperson, Pt Lincoln Aboriginal Aged, Disability and Carers Committee
Representative	SA Police, Port Lincoln

# Attachment 3

## Report on research conducted in Coober Pedy

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### **This report was prepared by:**

- Charlotte de Crespigny
- Inge Kowanko
- Carolyn Emden
- Helen Murray

### **Also involved in this project were:**

- Anita De Bellis, Mike Turner and Sharon Cruse from Flinders University
- Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council
- Coober Pedy Steering Committee comprising representatives of Umoona Tjutagku Health Service Inc. (particularly Anne Vanajek and John Bouilly), and other local health services and community organisations.

This local report will be published in 2003

## **Acknowledgments**

The project team acknowledges the generosity of the Aboriginal clients, carers, health workers and other people who shared their stories and insights. These participants cannot be named for confidentiality reasons, but their individual contributions are very much appreciated. We also thank the Coober Pedy Steering Committee members for their guidance and advice, and Umoona Tjutagku Health Service for hosting this section of the project. The project was supported by a grant from the Quality Use of Medicines Evaluation Program through the Commonwealth Department of Health and Aged Care.

## **Introduction**

### **A unique setting**

Coober Pedy is often called the 'opal capital of the world'. It is located 850 kilometres or 8-10 hours drive north of Adelaide. Since opal was first found in 1915, the town has attracted miners from around the globe and today has over 42 nationalities represented in the general community.

The country in which Coober Pedy sits is traditional land for the local Aboriginal people. In early days of white settlement many of the Aboriginal people 'noodled' (fossicked) for a living around mine shafts when the overlay was brought up from underground. When it was ruled that Aboriginal workers on stations should receive equal pay to white workers, many lost their pastoral jobs. Other market factors also affected their employment and subsequently they moved to towns like Coober Pedy [1](pp 5-6). Today, census figures are considered to under represent actual Aboriginal population numbers nationally. It is estimated that 500 - 700 Aboriginal people live in Umoona Community/Coober Pedy, with a further 150 visiting at any one time from other centres and the Anangu Pitjantjatjara Lands to the north. The total town population (non-Aboriginal and Aboriginal combined) is estimated to be approximately 3,400, with an additional 50,000 tourists estimated to visit annually [2](p 15).

## **State parameters: wellbeing and partnerships**

*The South Australian State Strategy and Action Plan for Social and Emotional Wellbeing for Aboriginal People* produced in May 2000 highlighted what many Aboriginal communities around South Australia had to say about poor social and emotional wellbeing and how they wished to address it [3]. The Plan includes valuable background information relevant to this project. For example, it is acknowledged that statistical information shows Indigenous Australians have had, and continue to have 'the worst health of all Australians' and comprise 'one of the most disadvantaged groups' in the country. This is supported by the most recent data from the Australian Institute of Health and Welfare (2001). This in turn places Aboriginal people 'at greater risk of ill health and reduced wellbeing than most other Australians' [3](p 15). The distinction is also well made in the Plan [3](pp 4-5) between the non-Aboriginal 'medicalised concept' of mental health (focusing on mental illness/disease and diagnoses of disorders), and the more culturally appropriate term used by many in the Aboriginal community, being 'social and emotional wellbeing'. Aboriginal people consider mental health in a wide context that includes environmental circumstances such as family, country, tradition, dispossession, poor economic factors, grief and lifelong ill health, characterised by the significantly shortened expected life span compared with non-Aboriginal Australians. This distinction is especially relevant to this project as it relates to the experiences and concerns of Aboriginal people with mental health disorders, including drug and alcohol problems, and their carers and other family members, and how they are treated by the health system.

The *State Strategy and Action Plan* cites the following local definition of social and emotional wellbeing provided by Maryanne Hudson of Umoona Tjutagku Health Service, Coober Pedy [3](p 5):

*Social and emotional wellbeing is having a happy lifestyle. It is having your physical needs met such as food, clothing and shelter; and also having the self esteem to cope with your life and your job while motivating yourself to achieve the goals and ambitions you set for yourself and your family. Living a healthy lifestyle and looking after yourself and your family is the Aboriginal way. Wellbeing is about having love, support and respect from your family, friends, community members and peer group; and being able to respect each other's opinion, culture and differences. Wellbeing is also about taking responsibility for our health and everything that we do.*

Further relevant information in the *State Strategy and Action Plan* is the 'partnership approach' [3](pp 8-9). This derives from a formal agreement between four major organisations in South Australia 'to work together on planning for better outcomes in Aboriginal health'. The partnership approach emphasises:

1. Joint work.
2. A focused approach to addressing the issues.
3. A commitment to involve Aboriginal people and communities at a local level.
4. Providing support at a local and regional level to assist in the development of coordinated action.

The partnership approach takes into consideration the fact that over the years numerous reports and recommendations have been produced with the intent to improve Aboriginal wellbeing - however many of these hopes and best intentions remain unfulfilled. The plan 'for relevant parties to work together in partnership' aims to help redress these unfulfilled aims, continuing poor health, and social and emotional distress.

By taking the partnership approach on board in this project, we aimed for very close collaboration between Aboriginal and non-Aboriginal individuals, groups and services in its design and implementation. To help ensure the project's success, we have endeavoured to work together, remain focused at the local level, and aim for coordinated action. (This posed a challenge at the outset of the project due to some resistance to participate among key non-Aboriginal service providers due to their perceived value of the project not aimed at people beyond the Aboriginal community. This may have been due to them not recognising why the Commonwealth had prioritised Quality Use of Medicines funding, specifically related to mental health problems, for Aboriginal communities in recognition of great need in this domain). This has also been the research team's experience in other regions included in this SA-wide project.

## **Local parameters: responses to specific health needs**

Recent initiatives pertaining specifically to the health and wellbeing of Aboriginal people in Coober Pedy, and occurring in part during the data collection period for this project, were:

- *The Mental Health Plan: Northern and Far Western Region*, produced by Jeff Fuller in December 2001 [4, 5].
- *The South Australian Aboriginal Health Services review of pharmacy services*, reported by Amanda Sanburg in 2001 [6].
- The *Coober Pedy Alcohol Strategy* produced in November 2000 by the Crime Prevention Unit, Attorney-General's Department [2].
- *The Health Needs Assessment Report of Coober Pedy and surrounding areas*, prepared by Merridy Rowe in December 2001 [1].

### ***The Mental Health Plan: Northern and Far Western Region***

This Plan was agreed to by a diverse group of 15 South Australian agencies involved with mental health, although it is unclear as to which Aboriginal groups were consulted and involved throughout its development. It has been based on seven objectives for the years 2001-2004, concerning: integrated care; mental health promotion; early intervention; emergency care; community capacity; consumer/carer/community involvement; and staff. Mental health was taken to include mental health disorders and problems, and social and emotional wellbeing of all people in the region, including Aboriginal people. It was stated that the Plan sits within a wide context of relevant national, state and regional health policies and plans [4](pp 1-3).

In relation to Coober Pedy, the Plan proposed specific action concerning integrated care, drugs and alcohol, domestic violence and counselling. While actions are relevant to the population in general, it is acknowledged that Aboriginal people have particular needs in these areas[4](pp 58-62). In Volume 2 of the Plan, for each area of concern, strategies, activities, process indicators, and impact indicators are outlined. The Plan does not specify a timeframe or individuals who will initiate the strategies, other than recommending that a 'local mental health reference group' be established. The Plan is thus very general in nature [5] (pp 34-38). There is no evidence of effective outcomes thus far.

### ***South Australian Aboriginal Health Services Review of Pharmacy Services***

This Review covered remote clinics where more than 50% of the clients were Aboriginal. The aim was to establish the impact of Section 100 (S100) of the *National Health Act*, which allows the Commonwealth Government to make alternative arrangements for the supply of medicines. Eligible Aboriginal Health Services can apply to the Commonwealth Department of Health and Aged Care under S100 to receive medicines in bulk and then supply them to patients in safe and appropriate ways. Aboriginal clients need not go to a



pharmacy to have prescriptions filled or pay for their medications. It is intended that the savings achieved by the Department of Human Services (as a result of the Commonwealth paying) be put back into Aboriginal communities for better medication management services [6].

At the time of the Review, the Aboriginal Health Service in Coober Pedy (Umoona Tjutagku) was not eligible for S100 arrangements. This situation has since changed, however, and S100 is in place. The review of four Commonwealth funded remote clinics in South Australia found an 'improved drug supply' with S100 arrangements in place. However, the savings made by the introduction of S100 were 'not necessarily' used to improve the quality use of medicines but went elsewhere, such as for wages in the health services. Some serious labelling and dispensing problems were found which have led to the implementation of training packages for Aboriginal health workers [7]. The Review states that Section 100 is 'not consistent' with Quality Use of Medicines: 'no medicines are labelled by the pharmacist and precautionary labels are not compulsory'. The Review also questions whether the 'one stop shop', whereby patients receive their medicines at the point of prescribing, actually improves safety, accessibility and compliance [6] (pp 1-4).

### ***Coober Pedy Alcohol Strategy***

This Strategy [2] is a State Government initiative, designed to address in a comprehensive and ongoing way the problems of alcohol misuse in Coober Pedy. It takes account of various earlier attempts by the local Aboriginal community and others to solve problems associated with excessive alcohol consumption in the town and surrounding areas. The Strategy is funded over a four-year period and implemented by an Adelaide-based implementation committee and a Coober Pedy-based advisory committee. Key components are intended to include:

- Mobile assistance patrol.
- Sobering up service.
- Liquor licensing restrictions.
- Day centre.
- Transient camps and gathering places.
- Rehabilitation.
- Early intervention/detection (2 pp 3-6).

However, it is concerning that to date only the mobile assistance team is operating and other components are 'on hold'.

The Strategy is intended as a multi-agency initiative aimed at addressing and preventing harmful alcohol consumption amongst people in public places in the town and near surrounds. It acknowledges the complexity of issues involved. For example: the role of family in social control; compensation for

loss of traditional ritual practice by drinking; group pressure to drink; the opportunistic nature of binge drinking; equating drinking with social equality; drinking to alter reality in the face of social marginalisation; and the fact that drinking among some Aboriginal people is often a collective act that generally takes place in the open (and therefore in public) [2](pp 34-35). The very nature of 'Dry Zones' is known to impact negatively on those groups who are homeless, and those who prefer to have cultural meetings and social gatherings 'outside' - not in 'conventional' non-Aboriginal household settings or licensed venues. This in itself has been found problematic in other communities such as Alice Springs, as it can reinforce the belief in the wider community that only Aboriginal people drink hazardedly, which is not supported by the evidence [8, 9], and further alienates these vulnerable groups and puts them at further risk. Recent anecdotal evidence suggests that there are already serious negative consequences for local Aboriginal people since implementing the strategy.

#### ***Health Needs Assessment Report of Coober Pedy***

This Report was initiated by a steering committee of the Regional Health Service - initially to address difficulties in retaining general medical practitioners in the community, and then to the further health needs and concerns of the community. It is about the entire Coober Pedy community (not just Aboriginal) and extends to the surrounding areas of Marla, Mintabie, Lambina and Seven Water Holes, Oodnadatta and local stations. Key issues (incorporating Aboriginal issues) were found to be: aged care and services for the disabled; allied health services; family/carers, children and youth health issues; confidentiality; dental service; diabetes; domestic violence; environmental health; general practitioner access issues; health education; health services; home help service; issues facing Coober Pedy agencies; mental health services; drug and alcohol services; services for women; and transport [1](pp 23-28).

Umoona Tjutagku Health Service Inc. is described in the Report [1](p 16) as an Aboriginal community controlled health service, funded by the Commonwealth Department for Health and Aged Care - Office of Aboriginal and Torres Strait Islander Health and SA Department of Human Services. Its focus is primary health care and in October 2001 it had funding for a domestic violence worker, a worker for *Bringing Them Home*, and a substance misuse worker. A registered nurse and up to four Aboriginal health workers have been employed to attend clinics, conduct home and hospital visits, attend to aged care, transport clients and deliver medications to clients. The two long-term resident doctors provide a service for their patients. During preparation of this report many staffing and governance changes have occurred at Umoona Tjutagku Health Service, and the mainstream services at Coober Pedy, resulting in serious disruption of core services and lack of integration and coordination at the local level between services, including safe medication services.

Umoona Aged Care Aboriginal Corporation was established in 1996 to provide services to Aboriginal Elders, including 'respite care, a traditional bush camp, socialisation program, home care, personal care and assistance with shopping, bill paying and banking'. Maintaining ongoing staffing levels is the biggest problem: a State-funded traineeship is available through the Spencer Institute of TAFE in Coober Pedy, but there is no funding for ongoing employment of graduates [1](p 16). It was thought the problem would be partially resolved by incorporating aged care beds for Aboriginal people into the hospital.

*The Health Needs Assessment Report of Coober Pedy* conveys a picture of a widely diverse community with complex needs - serviced by multiple organisations, agencies and health workers, some with overlapping roles. Despite many identified issues, the Aboriginal community has nominal access to a wide range of services, both mainstream and Aboriginal. Significantly for this project, no reported initiatives specifically addressed issues surrounding safe medication management for Aboriginal people with mental health disorders. However, statements made about inadequate nursing and medical staffing levels, lack of evidence-based clinical guidelines for hospital nurses and doctors to assess and effectively treat alcohol and other drugs, in particular alcohol withdrawal and intoxication-related medical problems (particularly in association with mental health problems) at Coober Pedy Hospital and Health Services, and an inability of the town to maintain an adequate pharmacy service were clearly relevant to the project. Currently (June 2003) the Umoona clinic has one registered nurse, one enrolled nurse, and a male and female health worker on staff. Funding for a medical service appropriate to the needs of Aboriginal people is being sought as the top priority. A health service operating without a resident GP can never meet the needs of such a community.

## **Aims and objectives**

The aim of the overall study (of which this project comprises one part) was to explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, and their carers and other family members, focusing on issues relating to management of medications. Mental health disorders included conditions such as depression, dementia, acute anxiety, schizophrenia, bipolar disorder, substance use disorders, grief and loss, and related emotional distress. The project was conducted in a range of metropolitan, rural and remote areas across South Australia, in collaboration with Aboriginal communities and other stakeholders. Findings from each area were considered separately as well as together, to inform local and SA-wide recommendations and strategies for improved, culturally appropriate policies and practices for safe medication management by

mentally ill Aboriginal Australians and their carers. A further aim of the study was to implement and evaluate some of these recommendations in selected areas.

This chapter reports on the findings and recommendations from the Coober Pedy area only. The research team has already completed a pilot study funded by an Australian Rotary Health Research Grant and conducted in Northern Metropolitan Adelaide [10]. The larger research project of which this is a part is funded by a Quality Use of Medicines grant from the Commonwealth of Australia Department of Health and Ageing.

## **Participants and methods**

### **Research approach**

A collaborative approach was taken involving a partnership between the investigators from the School of Nursing and Midwifery at Flinders University and the Aboriginal Drug and Alcohol Council (SA) Inc. The research was planned and conducted in consultation with a steering group of Aboriginal and mainstream service providers and Aboriginal people from Coober Pedy. This was to ensure the research was responsive to the needs of the Aboriginal community and conducted in a culturally acceptable manner. The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of SA. The research conformed to the National Health and Medical Research Council (NHMRC) guidelines for ethical Indigenous research [11]. It was also deemed appropriate by the local host Aboriginal service with whom we worked.

#### ***Steering Committee***

A local steering committee comprised the research team, representatives of Aboriginal groups in the Coober Pedy area, and those who provide health and social services to the client group and their families. The committee was convened in early 2001 to guide all aspects of the research, and met several times over the next 18 months. This committee was invited to advise on recruitment of an Aboriginal research assistant acceptable to local Aboriginal communities, engaging potential participants, drafting and piloting the interview guide, follow-up on issues raised by the local Aboriginal research assistant on behalf of anonymous interview participants, and draft reports and recommendations. We have used a similar approach successfully for previous research on medication use by Aboriginal people with mental health disorders [10], medication use by older Aboriginal women [12], and other research [13, 14].

## Data collection

Data collection occurred between March 2001 and July 2002. Data were collected through in-depth interviews and focus groups with consumers and service providers. Potential interview participants included adult Aboriginal people diagnosed with a mental health disorder, or culturally determined social or emotional wellbeing problem, their carers or other adult family members, and workers living in Coober Pedy. The Aboriginal research assistant or an acceptable member of the research team contacted them and invited them to be interviewed for the project.

Inclusion criteria for service providers were that they provide professional health services or social support to Aboriginal people diagnosed with, or experiencing a mental health (social and emotional wellbeing) disorder, their carers or other family members. Purposive and opportunistic sampling strategies were used to gain a range of voices and viewpoints.

An Aboriginal research assistant or another member of the research team conducted one-to-one interviews and focus groups with groups of people, following an interview guide (appended to chapter 5). These conversations were recorded on audiotape or in writing, with the participants' informed consent. Participants were assured of confidentiality and anonymity, and could choose not to answer any question and withdraw consent at any time. The interviewer made notes (written and/or taped) to supplement the interviews.

There was a total of 15 Aboriginal and non-Aboriginal participants. Conversations with members of the steering committee also informed the project. There were six interviews and three focus groups. Participants were Aboriginal community members, Aboriginal and non-Aboriginal health and community workers and other service providers. Most Aboriginal participants had experience of social and emotional distress in their community, either personally and/or as carers or other family members.

Tapes and hand written notes were transcribed verbatim. Where possible, the Aboriginal interviewer, who had been trained by this research team, checked the accuracy of transcripts and assisted with local terminology and language. Consultation also occurred with an Aboriginal member of the research team familiar with local language, terminology and cultural issues.

In addition to data collected in the above interviews and focus groups, further relevant information was derived from taped debriefing conversations (between Aboriginal and non-Aboriginal research team members) and recorded reflections by research team members following a steering committee meeting. Contextual information gained through frequent telephone contacts and several visits to Coober Pedy was also used.

## **Data analysis**

Preliminary qualitative analysis of each interview and focus group transcript was conducted, based on the six main headings in the interview guide: demographics; use of health care and other community services; medicines; mental health; alcohol and other drugs; and difficulties for people with mental health problems. Key information and quotes from interviews were coded under those headings while reading and re-reading the transcripts. These were then categorised further into themes, based on the issues and concepts mentioned in the grant application and interview guide, and others that emerged from the interviews. Finally, all findings were integrated into one summary document to give an overall picture highlighting common themes and key issues [15]. Findings were presented to steering committee members and key informants for further elaboration and validation. Notes from these meetings were included as data where appropriate.

In this chapter, quotes from research participants are included in inverted commas (very short quotes) or italics (longer quotes), without any identifying reference to the person making the statement, unless appropriate. For clarity of quotes, the 'ers' and 'ums' of conversational language are omitted. In keeping with confidentiality agreements, individuals are referred to in various generic terms such as 'health workers', 'service providers', 'research participants' or 'research team members'. Aboriginality and non-Aboriginality are generally not highlighted.

## **Findings**

### **Demographics**

Participants were predominantly Aboriginal with some being local non-Aboriginal health or welfare professionals. All lived in Coober Pedy. Some had lived in the region all their lives, others had arrived only months ago. Three Coober Pedy Hospital and Health Services non-Aboriginal staff reported having been employed for only short periods at the hospital (3-12 months). Participants were female and male, married and single, with and without children at home. The participants' jobs included youth work, government employment within Aboriginal communities, medical practice, and mental health and community nursing. Several participants reported speaking an Aboriginal language. Generally, demographics were diverse on all measures except place of residence.

### **Use of health care and other community services**

#### ***General health issues***

Service providers highlighted the prevalence of numerous chronic illnesses and 'undiagnosed and unmanaged conditions of all sorts' among their Aboriginal clients. Issues related to poverty ('hand-to-mouth existence week

by week with people living cheque to cheque'), psychological issues, stolen generation issues and issues related to alcohol abuse and substance misuse were all cited as highly relevant to the health status of the Aboriginal people they saw in their work as health practitioners.

The worker participants reported the following as common health issues for their clients: dementia; alcohol problems; social and emotional problems; dietary problems; chronic heart problems; liver problems; kidney problems; diabetes; chest problems; bronchitis; emphysema; eye and ear problems; bowel problems; and poor eye sight and motor coordination.

They especially highlighted that Aboriginal Elders have seen 'huge dietary changes' in their lives, which exacerbated their health problems - from 'traditional bush tucker', to 'stockman-type salted beef', to 'western take-away'. Nutrition programs had a history of being unsuccessful because people had other priorities ('you're not going to get nutrition through to somebody who is hungry') or lacked transport:

*...the only logical way of getting food home for your family in the community, if you haven't got your own vehicle, which a lot of people haven't, is to carry take-away.*

The problem of take-away was compounded by it being expensive. Consequently there was not enough food to go around the number of people - often swelled by friends and extended family members visiting or passing through. As well, money regularly ran out: 'they eat well on pay day and for the rest of the time they're not eating'.

In relation to nutrition, the health workers believed the Aboriginal people they serviced needed support systems rather than information. They stated that a community shop selling readily available, reasonably priced, healthy foods was needed, as well as transport from the community to the town. The distance from the town to the community was seen as too far to carry shopping on foot (it was estimated twice as many Aboriginal people lived in the Umoona Community on the outskirts of Coober Pedy as in the town itself).

### **General health services**

Services provided by Coober Pedy Hospital and Health Services at the time of data collection were reported to be:

- accident and emergency, with an estimated 50% of presentations being injury or alcohol-related;
- ongoing medical management of patients;
- some minor surgery (since the use of locums);
- antenatal and postnatal care;
- community health, including counselling, medication support, case

- management and assessment of referrals from agencies, and 'outback packages' for elderly individuals requiring special assistance;
- part-time mental health nursing service (2 days a fortnight);
- a range of specialist medical services on a periodic visiting basis.

Participants considered the most urgent general needs for Aboriginal clients related to culturally safe and accessible drug and alcohol services (including a properly resourced detoxification unit), mental health services (including adolescent mental health services) and a pharmacy service. Some health professionals felt that there was a need for local antenatal care, a midwife and facilities to handle uncomplicated deliveries, an ultrasound machine, and facilities to link with tele-health. Interpreting services, although not available in the town, were considered non-urgent, as a local untrained interpreter could usually be found for local Aboriginal clients. However, there are issues that need addressing in relation to lack of anonymity and traditions/practices requiring 'same gender'. Generally, health professionals reported that they would like more doctors, registered nurses and medical equipment in the town. To attract multi-skilled staff, better salary, work conditions and family-oriented packages would need to be made available.

The services of Umoona Tjutagku Health Service were described as: dissemination of health information via word of mouth; screening for early signs of diabetes - hearing loss, diminishing sight, increasing blood pressure; medications delivery; transport of Elders and others to/from appointments; accompanying children to the medical specialist; making appointments for clients; reading mail and writing letters for Elders and others with poor eyesight or who are illiterate in English; making phone calls for people; and narrative therapy related to the Bringing Them Home project. The Aboriginal health workers identified transport of their clients, including to and from the bush camp, as a major, but under-resourced need: 'We are trying to run three vehicles off one fuel budget'. Consideration was being given to administering a charge for transport outside usual activities to help meet this need, but there were doubts as to the fairness and feasibility of this, with poor likelihood of realistically recouping monies from impoverished clients. The ethics of refusing services for those who did not or cannot pay also made this unrealistic.

Umoona Aged Care Services were described as home and community care services for Aboriginal people whether they lived in a 'traditional, semi-traditional or urban setting'. They included domestic assistance, social support, advocacy and:

*... anything to do with keeping a person safe in their own home so that they don't have to go into facilities or leave town to pick up a service.*



Nutritional problems were identified as a major concern, for example: 'Not being able to maintain the quality of food ... it's rather a binge food thing'. Programs were being implemented to address the necessity of having fridges, freezers, heating and cooling in houses. As one participant put it: 'The low socio-economics, that does really impact on their health needs'.

In discussing the provision of specialist and allied health services, some service providers considered the range of services to be very wide: 'It's really well covered'. This was considered a much-improved position to two years previously, when 'it was just about impossible to access mainstream services'. One person commented that waiting lists for specialist appointments were long. There were also moves to improve and increase screening programs for children (for example, for ear nose and throat, and eye problems). In terms of overlap of services, one participant considered there was 'room for improvement' in distinguishing between the services of Umoona Tjutagku Health Service and Umoona Aged Care Services:

*...there's still a lot of areas where health is mixed up with aged care...there needs to be some awareness campaigns...or education...the guidelines and the roles and responsibilities get a bit mixed up at times.*

### **Mental health services**

The only mental health service reported by participants was that of a part-time mental health nurse seconded from Whyalla two days a fortnight, and whose clients came from the Aboriginal and non-Aboriginal communities in Coober Pedy, resulting in long waiting lists and no capacity to adequately monitor, counsel and support, manage medications or deal with crises. There was some general backup from incidental non-specialised expertise of local practitioners. There was no support system in place dedicated to adolescent or adult Aboriginal mental health clients or their carers/families. All participants considered mental health services to be totally inadequate and the general consensus was that the position of at least one experienced mental health nurse should be full-time and permanent - something they hoped would eventuate with some anticipated regional funding.

One participant summed up the difficulty like this:

*There's not somebody there available when you need it...there's a waiting time. Sometimes you might need to get someone seen straight away and by the time they do get in to see somebody, the sets of issues have changed.*

Another participant pointed to the likelihood of ignorance of people's mental health problems in the community 'without the guidance of somebody who's trained, then their issues go unnoticed'. In a conversation

related to stolen generation issues, a health worker stated:

*We need to have our own...female and male mental health workers up here. Based in the community where people got access to them. So they can sit and counsel them.*

The workers also wanted the services to be accessible 24 hours a day, seven days a week.

One participant reported very favourably about staff positions (at the time of data collection) being put in place in relation to substance abuse, domestic violence and *Bringing Them Home* programs. She said Aboriginal people were being encouraged to use mainstream services as well as those designed only for Aboriginal people.

#### *Involving carers and other family members*

Umoona Aged Care Services ran a respite program for carers:

*We aim to help carers as well, so if a client does have a carer then we are funded to assist those carers in their roles as well.*

This appeared to be the only formal support mechanism available. It was reported that family members were caring for older people and this included older people caring for other older people, but without any financial support or benefits. For example, one health worker said of her own situation (in which there was no financial support):

*...my auntie was actually the carer but we'd helped her care for him, so it was sort of like, yeah, all the family sort of helping each other.*

One of the research team members, in a debriefing conversation, reported on observations in Coober Pedy:

*You know, older people are health service providers - older people provide care for their children, and also look after their children's children. They often go without medication themselves, because they can't afford to pay for it.*

A research participant described the extra pressure on a family when they had to care for a sick member, especially when they didn't have basic needs such as furniture, white goods and bedding:

*...we can't expect people to look after themselves let alone any ill family member if they haven't got the basic furniture in the house.*

This participant reported that through the 'anti-poverty program', there were inter-agency efforts being put in place to ensure families had adequate furniture and basic requirements to run their houses.

### ***General practitioners***

Two doctors in private practice and one employed by the hospital provided general practitioner services. The hospital provided a 24-hour accident and emergency service triaged by a registered nurse.

The major issue for the medical practitioners was that the hospital's accident and emergency department was treated by Aboriginal people as an all-hours consulting service: 'Basically they've been allowed in the past to come in and say, 'I want to see the doctor''. Another participant stated the problem as: 'There hasn't been sufficient triaging going on - distinguishing between what's been emergencies and what hasn't'. This had placed great strain on the hospital doctor, who at times had been on 24-hour call. It was stated to be 'unacceptable these days to have one doctor on call 24 hours a day, seven days a week, no matter where you are', for both the community and the doctor. It was clear that the hospital and general practitioners in town saw that the registered nurse on duty should implement the triage system more strictly. However, it was agreed this was difficult when Aboriginal clients refused to have an appointment at another time, saying they would not leave until they saw the doctor. Moves were under way to change this 'culture' of expecting immediate attention, whatever the time, by explanations in the local paper. Whether this would reach many members of the Aboriginal community is a moot point when English is not the first language for many traditional people, who come down from the lands where they are used to attending the clinic when in need, and illiteracy rates are high amongst local and transient Aboriginal people. Access to newspapers of course is a major issue, especially if this alone is relied on as the means of informing and educating this community.

It has been argued that if the hospital, general practitioners and Umoona health workers collaborated, a more accessible outreach clinic could better service Aboriginal groups in camps and outer town areas, for example an evening clinic several times a week may well reduce pressure on scant hospital services and serve the people better. It would also change the 'culture' of asking for hospital services after hours, as is currently the case. It also needs to be considered that in this harsh environment where ambient temperatures can be up to 50 degrees C at midday, elderly and sick people may well choose not to come to the hospital in during the day as they have difficulty walking long distances in this extreme heat to attend during appointed hospital hours.

Another related issue identified was Aboriginal people asking to be admitted to hospital. As one participant said:

*...they think of the hospital as a hostel cum sobering up unit. It's not because they're sick they want to come in here. They haven't got any money left for food, so they turn up at the hospital ... this always usually*

*comes on a Monday or Tuesday, so their pay check's not due until Thursday ... come payday, they walk out.*

The different 'culture' that the hospital leaders and local doctors were trying to put in place emphasised that in their opinion it was not for a patient to say they need to be admitted, but for the doctor to identify a medical reason, 'not just because you haven't got any money left'. If Aboriginal clients did not achieve their wish to be admitted, anger could result. One participant told of an instance when the patient did not directly communicate her wish to be admitted to him and it was only when he saw her angrily discard the prescription he had written into the rubbish bin that he realised this.

Some participants also raised 'doctor shopping' as an issue. As one said, there were 'three doctors in the town who have different medical records for the same person'. This was apparent in a particular anecdote shared by a participant who had tried to assist a client in pain by ringing around the client's doctors for an appointment. Another reported knowledge of people continually taking Panadeine Forte:

*People will doctor shop to get that. They will go to the hospital in the middle of the night with all sorts of stories to obtain more. I know some people who have been doing that for years.*

The workers suggested that there should be more information transferred between doctors ('a link-up between each other'), with the client's consent. There was no mention at this stage of the need for health worker, patient and local community education about this issue.

Failure of some Aboriginal people to keep appointments with the general practitioners or arriving late for appointments was highlighted as a further issue. Some health workers perceived the basis of this problem being over reliance on assistance. As one observed:

*People sit at home (and) say 'I missed my doctor's appointment.' 'Why did you miss your doctor's appointment?' 'No one come and pick me up.' Despite the fact that they have a car and could have got there quite easy.*

Another service provider stated:

*People have got so used to the health workers being there and doing things for them  
... there's an expectation that if they've got a car parked in the driveway, they still expect the health worker to come and pick them up to take them to appointments.*

One participant reported she had been advised in writing that a general practitioner was withdrawing his services to Aboriginal people on account of the appointments issue:

*He stated that he is losing too much business because people are not keeping their appointments or running late for their appointments.*

The problem was summed up by one participant who said: 'Everything has a timeframe (but) our clients aren't working to timeframes'. It was also acknowledged that a 'smaller group' of Aboriginal people did make their own appointments and kept them.

On the timeframe issue (albeit in the different context of providing research data on time), one of the research team members, in a debriefing conversation, called for more understanding of the way Aboriginal community timeframes work:

*... there are certain community issues ... which will often disrupt projects like ours... For example, on the weekend in Port Augusta you know, there was this tragic car accident, which will no doubt dominate a lot of people including the people in the health services. You know, take over their minds, and they will spend time thinking about, and dealing with, the trauma that goes with something like that. ... So it's really important that we include in our reporting something that reflects our appreciation and understanding of the way the community frame works - time frames are often different to the time frames that we set ourselves.*

## **Medicines**

### ***Types of medicines***

Types of medications mentioned by participants as being used by Aboriginal clients included: pain killers (especially the paracetamol drugs, Panadol and Panadeine forte); antibiotics; anti-inflammatory drugs; medications for heart disease and diabetes; tranquillisers; sedatives and psychotropic medications.

### ***Managing and monitoring medication***

One doctor stated Panadol seemed 'to be used for just about anything', and it was not uncommon for Aboriginal people to ask for something stronger when it didn't work. It was his opinion, however, that while most doctors would 'resist dishing out unnecessary medication', others would 'probably acquiesce to the demands made of them'.

When asked about the adequacy of doctors' explanations of medications, this doctor thought there was not enough explanation in the health system generally and that financial pressures upon general practices meant 'people are being churned through at a rapid rate' with little time for explanations. He said it was the same when Aboriginal people got discharged from hospital:

*...they've been in there and they don't know what's wrong with them, what the diagnosis was, or what the medications are for.*

He was more optimistic that Aboriginal people with chronic illnesses knew what their medication was for. It was also this doctor's opinion that a lot of Aboriginal people don't want a prescription:

*...they want the pills supplied to them ... (it's) one of the things that makes Aboriginal medical services a little different from standard GP practices, because they do make an effort to supply medication when they know ... a prescription's just not ever going to make it to the chemist.*

Managing medication by way of seven-day dosette boxes (boxes with individual compartments to hold tablets for each day of the week) prepared by a registered nurse, or Webster packs (sealed bubble/blister packs) attracted many comments from participants, especially the Aboriginal health workers who were responsible for ensuring their clients actually took their medication correctly. One participant said many Elders needed very close supervision because of poor eyesight and that:

*...a lot of them haven't got fine motor in their fingers for picking up tablets or for getting them out of dosettes.*

This same worker shared the following vivid anecdote:

*I have actually witnessed clients when I've been out bush with them, sit down with a dosette and take out all the red ones because they like taking the red ones, not the others. I have witnessed where a dosette got turned upside down on the dirt and dogs sort of grab a couple of tablets and then the rest of them go back in all sorts of places, not where they originally were.*

Previous research undertaken by this project's chief investigator supports this finding. The doctors also regarded dosette boxes as unreliable with one saying:

*...quite often they come back within two days 'cos the kids have got to them and thrown them up in the air so the whole box is mixed up, so it's all got to be redone.*

Another participant commented that 'these dosette boxes ... they're stuck together with bandaids and they're pretty filthy sometimes', and reported that from his experience in another remote region, compliance was a problem with dosette boxes. Aboriginal clients would often report having lost their boxes or that they had run out of tablets, when in fact not all medicines from the box had been taken.

Blister or bubble packs have the tablets sealed inside individual partitions from which tablets are pushed out. These are prepared by a pharmacist. These were reported as being a superior option to dosette boxes, however without the services of a local pharmacist with appropriate equipment, this option was not possible.

Aboriginal health workers reported various experiences of concern to them. For example, citing antibiotics that were half taken: 'Instead of taking the full course ... (as) soon as they feel better, they'll stop takin' 'em'. Also, it was reported that Elders often don't understand the need for a repeat prescription to be filled or that if they are on different medications prescribed by different doctors, these might interact adversely. Illiteracy added to the problem, because 'when ... they can't read, they think, well one of them gave them to me, I'll just take them'. Taking medication within a specific timeframe (for example, four-hourly) was also problematic, because 'somebody might be just taking them willy-nilly', or 'Oh I forgot to take my tablets'. For this reason, one of the doctors stated he preferred to give an antibiotic by injection:

*...at least you know then that there's going to be some kind of impact. Whereas with tablets, they just ... forget.*

The Aboriginal health workers emphasised a need for ongoing repetitive reinforcement of information about medications 'over a very long time' for Elders - 'that's the traditional way of learning'. They also called for more education (some was reportedly underway) on the client's role and responsibility in relation to medication, because 'a lot of clients feel that it's a worker's job to make sure that they've got, say their tablets'. They said it would be good for clients to see some things as their responsibility, not the worker's. But medications may not always be a priority for some clients, as illustrated in this comment from an Aboriginal health worker:

*The clients ... they're aged people so they don't sort of think, 'Oh, medication tomorrow morning', they get up and think, 'Oh, I'm going to Port Augusta today'.*

### ***Feelings about medication***

Participants said they believed many Aboriginal clients had 'very little' trust in their doctors when it came to medication 'because it's probably not explained to them in terms that they understand', and this may have a major influence on decisions whether to take medication or not. Traditional people were especially reticent to use medicine, 'particularly if it's medication that's going to dope them up a bit. They're very fearful. They usually won't be compliant with that'. One participant said she didn't really like taking medications herself - only 'when I have to, like antibiotics ... even Panadol ... only if I have to' and that included her children.

Of great concern to one participant was the apparent irresponsible behaviour in relation to medication usage (for example, management of diabetes medication) by some Aboriginal people who were assumed to be 'educated and should know better'. There was a suggestion that Aboriginal health workers should have more education in relation to medication usage 'because they're the ones that actually go out and give the medication out'. It

was of special concern that there was little understanding (among clients and workers) of the affect alcohol might have on the action of medications. Subsequent to this finding, which was also reflected in the other study areas, worker training on safe medication management in the community is now provided by this team (Chapter 9).

### ***Cost of medications***

Some participants considered cost of medications an issue for Aboriginal people. They said that health workers at Umoona had access to some emergency money (from Child Health and Aged Care services) for situations where the doctor had written a script but the Aboriginal person 'had no way of getting it filled because they didn't have the funds to do it'. This could be a particular problem for people coming down from the Lands 'where they're used to getting free medication', and those with chronic illnesses that required multiple medications on a regular basis. As well, on top of the cost of the medicines, 'they're paying freight'. We were also told that deductions from Centrelink payments for the cost of essential medicines could sometimes be arranged. Umoona staff participants spoke of paying for some needy clients' medicines themselves. From another participant's perspective, doctors did not view cost as a problem, as 'most people seem to be able to somehow get the money'. The recently instigated S100 arrangements have helped, since needy clients can obtain their medicines at no charge from Umoona Clinic.

### ***Delivery of medications***

Because Coober Pedy had no resident pharmacist, prescriptions were faxed to Adelaide or Port Augusta where medications were dispensed and delivered back to Coober Pedy on a regular basis (it was mentioned that two doctors had some dispensing rights but this was not elaborated upon). At the hospital, the registered nurse placed the medications in dosette boxes according to the doctor's orders (note that since the implementation of S100 arrangements the registered nurse at Umoona Tjutagku Health Service now makes up dosettes according to the doctor's prescription). Aboriginal Health workers from Umoona Tjutagku Health Service then delivered the dosettes to clients - weekly, daily or twice daily if necessary. Most Elders were said to require the daily or twice daily service.

The delivery service to clients was continued over weekends and on public holidays by community health staff, in conjunction with delivery of meals. It was said this sometimes posed a problem:

*...if that client doesn't happen to be there at that meal time, the medicines were being left and they were still there on the window ledge Monday morning.*

An untrained worker might then inappropriately give the person the medication on the Monday morning, leading to an overdose, or a child



might 'grab them'. Delay in getting medication to clients in their particular location was also likely, as one participant described:

*What you have here is you have your people that move around, so it may take you an hour, three hours, to find the client, but somebody else could go out in another community and just go to their house and just give it, it's a 10 minute job, whereas here, it may be a 2 hour job.*

In the absence of a local chemist, it was stated medications sometimes 'went missing' in transit from Adelaide, which meant clients were without medication until another delivery could be arranged. However, we note that the introduction of S100 arrangements for medication dispensing from Umoona Clinic (which occurred after data collection period) has improved the situation.

#### ***Sharing and storing medications***

It was apparent some sharing of medications did occur amongst Aboriginal family members. One participant said it sometimes came to her hearing 'that somebody has shared their tablets with somebody else because they think they've got a similar thing wrong'. Another reported a situation where a client was found to have someone else's dosette box.

One participant, who was a service provider, said people will take others' tablets 'if they're into looking for buzzes or sleeping for a couple of days'. They like to try others' tablets that are stronger than their own or may get others' tablets to sell, which 'makes the issue even worse because we don't know who it is and who's actually taking them on top of what they are taking'.

Medication storage was also considered a problem in some homes, especially for heat sensitive medications in homes or camps without a refrigerator. Health workers said they would like to see more cultural awareness education for staff in the doctors' clinics:

*I've heard a nurse say to a young mum, 'You have to keep that medication in a fridge' and 'cause mum hasn't got a fridge and she's embarrassed about it or too shy to talk to the nurse, she'll walk out the door and throw the medication in the garden. Whereas if they actually said to them, 'Have you got a fridge?' and if they said no, 'Dig a hole and bury it, keep it cool'. Giving them some alternative ways of keeping it cool would perhaps avoid it being thrown away.*

Regarding disposal of medications, it was reported that some people did dispose of them appropriately (for example, flushing them down the toilet) while others had 'multiple amounts of perhaps the same medications, carrying them around in their handbags'. It was felt people tended not to discard their medicine. 'A lot of them keep it ... and then they go to reuse it

... like some old cough medicine or something'. It was pointed out that with many clients being illiterate, instructions on how to take and store the medication, possible side effects and use-by dates were meaningless. One participant who was a health worker said she would not take her medication if it were out of date, however generally there was little knowledge amongst workers or community members about these important issues.

## **Mental health (social and emotional wellbeing)**

### ***Understandings of mental health***

The Aboriginal service providers considered they had a good understanding of mental health from their personal experiences as workers, as well as their own families and friends. One participant had been brought up in a 'kids home' and found it sad that 'a lot of the kids that got sexually abused or abused badly in the home have ended up in and out of mental institutions'.

The health workers reported many of their community Elders had Alzheimer's and alcohol related dementia, also old head injuries. In younger people, 'drug induced psychosis', brain damage from petrol sniffing at some stage, and 'hereditary type psychosis' were mentioned. They said 'you have young people saying they're hearing voices telling them to do things' and 'they see a lot of things which we don't see as normal people'. The workers said it was hard to know if these features were the result of taking illicit drugs or schizophrenia - a 'label' that they said seemed to be increasingly used. Stress was reported of concern for young people because of family issues at home and not being able to get 'whatever they smoke'. They were not sleeping and were taking their stress to work, which in turn created other problems in relation to unsatisfactory work performance.

'Aboriginal spirituality' had 'a lot to do with healing mental illnesses', according to the Aboriginal health workers, especially in the Coober Pedy area. They said there was confusion because there were 'two churches in town that are teaching that traditional beliefs are evil and of the devil' - leaving some Elders feeling 'very guilty and ashamed'. As part of this conversation, the health workers called for traditional healers to work with the 'mental health doctor or nurse', so each could explain their perspective to clients. As one worker said, 'somewhere along the line I think they're going to have to work together'.

The non-Aboriginal service providers offered various views on their understanding of mental health, including the opinion that schizophrenia, depression and stress were not very prevalent among Aboriginal people, but that Aboriginal people didn't 'come to terms' with grief very well. Another said he always tended to assume depression was present 'because of the need to drink', 'anaesthetising yourself'. Yet another said 'psychological issues'

were 'many and varied' among Aboriginal people but that these usually didn't 'present as the medical problem unless there's some traumatic incident or someone's bashed up'. One participant did not find the psychiatric diagnosis system very helpful, and found the term 'personality disorder' more apt - amounting to 'upheaval and imbalance'.

### ***Social and emotional wellbeing issues in the Coober Pedy region***

All participants touched upon social and emotional wellbeing issues in the course of addressing other topics, indeed whenever they spoke about lifestyle, family and cultural issues. The Aboriginal service providers frequently called for a more 'cultural' and 'holistic' understanding of Aboriginal problems, while the non-Aboriginal service providers believed that they did understand these problems from their perspective. For example, one participant expressed his understanding of what he believed it was like for Aboriginal people who found themselves marginalised if they tried 'to belong to the white culture', or didn't conform to the expectations (such as drinking) of their peer group:

*So it's hard, hard to normalise your lifestyle ... so I guess a lot of people just give in, in the end, and ... I actually think that Aboriginal people generally seem to lack any sort of meaning in their life. They tend to come in and they describe existing, but they don't seem to ever - their testimony is never one of meaning or purpose, except for a few individuals. It's always more a theme of just existing. Just existing ... you very rarely hear them talking about some goals, or setting goals...*

The issue of different cultural expectations, experiences and ways of thinking between Aboriginal and non-Aboriginal people was clearly very challenging for the participants. For example, in discussing medication problems, one non-Aboriginal participant stated that in his experience, in the Aboriginal culture, health is not rated highly on the list of priorities:

*...when I was going amongst them, they really just didn't care ... they could see the effects it would have, not being compliant, but they didn't seem to worry about it, and especially where there's drugs and alcohol involved.*

Another related an experience where an Aboriginal patient had required a skin graft to an extensive leg wound after ten days of preparatory healing. Instead of staying in hospital after surgery 'for proper rest and care', she 'just walked out ... walking off somewhere just to enjoy the day' - jeopardising all that had gone before. This person said that when managing Aboriginal patients, you had to realise their level of discipline 'does not include postponing of gratification', indicating perhaps a lack of understanding of differences in cultural and life experiences, and priorities.

A major issue raised by the research team members (in debriefing conversations and reflections) as a result of their observations and conversations in Coober Pedy was what they described as 'institutional, overt, covert and individual racism'. One person stated it was much more apparent and 'in your face' in Coober Pedy than in Adelaide - it seemed 'to have become part of the culture of health service provision' in Coober Pedy. This person cited an instance where a mainstream service was reportedly refused to an older Aboriginal man. Also, an Aboriginal health worker believed mainstream service providers in Coober Pedy didn't consider Aboriginal people to be part of their client base. A research team member shared the impression, gained at meetings, that people were 'frustrated' and 'devastated' that:

*...particularly older community members are refused adequate care, that people's lives are put at risk, and it seems that Aboriginal people who are least able to advocate for themselves and even when they do have advocates they are still blocked from having appropriate medical and nursing care, particularly through the hospital and doctors' services.*

Many of the conversations about social and emotional wellbeing issues (with both Aboriginal and non-Aboriginal service providers) culminated in stressing the need for Aboriginal people to take increased responsibility for their own wellbeing. They realised it was very challenging to put strategies in place to help people work towards being better able to assume responsibility for their health, from the non-Aboriginal perspective, when they were reliant on various services. Nevertheless, as one participant said:

*So I always say that the whole process, if you could, still has to be an education for people taking care of their own responsibilities, being responsible for your own life really, ultimately.*

### ***Effects of mental health problems on families***

The health workers told many anecdotes where mental health issues impacted on family life. The family was considered 'the crux of the problem' (whether drug or alcohol related) for children:

*They're not listening to the problems that the kid is saying that's wrong with the family. There is a big fight between mum and the kid. They're kicked out of the house yet again to wander around.*

Another participant illustrated the potential complexity of the family situation:

*Then you've got the other side of that too where people have been accused of being possessed ... or having done something wrong to deserve the problem that they've got.*

One participant considered that the mix of mental health problems and alcohol consumption also caused many difficulties. She believed people talk

about 'the deep issues' when they are drunk, however:

*...the family may not be drinkers and they would hear the same story all the time when the person's drunk and they don't know how to deal with it. Other than getting angry with them. Kicking them out of the house. Which just makes the problem worse.*

Mixing medications and alcohol also creates difficulties:

*...Aboriginal people that I've known of, threaten their family members and say 'You don't care about me, so I'm going to take all my tablets'. And they wash it down with a glass or swig of grog. Just to make the family feel guilty.*

Poverty, poker machines and extended hotel hours were considered major factors associated with the breakdown of Aboriginal family networks. This in turn created 'a whole new problem' for families and the community - 'it just snowballs'.

Some participants highlighted Stolen generation issues, especially the inability of untrained health workers to cope with the specialised counselling required:

*...we're just not equipped to deal with the traumas of someone coming back looking for their parents ... they're rejected a second time. There's a big cultural gap there. You could end up with the returned child being totally confused, not accepted ... the gap that's between the cultural family up here and where that person's been brought up ... is massive...*

One participant, who was also a service provider, spoke at length of her own (many years earlier) diagnosis of bipolar disorder: the difficulty of recognising she would benefit from medication; facing the costs of medication; and handling the associated stigma (people thinking she had gone 'nuts'). This participant shared that she had finally accepted she would need medication for the rest of her life, and that the same condition existed among other family members. Talking with a psychiatrist had enabled her to come to terms with previously unresolved issues from her past.

Looking back on her working life, she realised it had been spent helping other people and that it was a positive experience to focus on her own mental health for a change. This participant provided valuable insight into how personal experience can have a powerful and positive impact on one's work:

*You are more able to help other people that are suffering because you are on the same level, so to speak. You know, you've been there, you've done that, you're still doing it. And you're more able to recommend that they stay on their tablets. You are more able to recognise the possibility that someone, whoever you're dealing with, may have some sort of mental*

*illness by the way they act, the way they walk. The way they do bizarre things. And then you're able to provide that extra counselling or recommend that they go and get some sort of treatment.*

### ***Traditional practices***

The Aboriginal health workers had views and experiences about traditional practices. One said 'some psychosis does seem to start being very fearful of payback and traditional law'. She had witnessed a person experiencing 'extreme paranoia' about being killed in relation to a traditional issue 'up at the Lands'. One participant believed traditional medicine worked for Aboriginal people because 'it's based on psychological and spiritual healing'. Also, some traditional ointments were still being made and 'assisted a lot of people'.

One of the Aboriginal research team members, in a debriefing conversation, stated that many Aboriginal people in Coober Pedy had a 'traditionally oriented background' but that this was not well understood by the mainstream services. This person described Aboriginal people, particularly elderly people, as 'straddling two worlds' and believing in spirit, rather than germ, as a cause of disease. It was said that, while doctors in Coober Pedy were seen as attempting to take this into account, 'often it doesn't work out that way in reality for the client'.

There was wide support for the use of traditional healers in conjunction with non-Aboriginal medical practice. The fee structure for these traditional healers was reportedly in dispute, where some wished to receive only a small gift while others would like a fee equivalent to medical doctors ('we're using our special skills to heal therefore we've got to be paid accordingly'). The problem was seen as being that 'the Government hasn't seen them as doctors yet'. These participants were unaware that the SA Department of Human Services has made funds available for traditional healers on a trial basis, as reported by Aboriginal service providers involved in this project from the Port Augusta region (Attachment 1).

## **Alcohol and other drugs**

### ***Types of substance misuse***

On alcohol and other drug use in general, one health worker said: 'It's horrendous. It's horrendous and it's getting worse'. Several participants indicated their clients might be addicted to Panadeine forte. The most common illicit drugs were considered to be amphetamines (by snorting and injection) and cannabis, with occasional heroin use. Marijuana was reportedly often used every day, with some people allegedly smoking 30 -60 cones or 'joints' a day. It was pointed out that in contrast to ten years ago when drugs were 'behind doors', today there is a 'free access' on the streets

'at small cost'. There was no formal reporting amongst these participants regarding use of other illicit drugs, however informal discussions indicated that there are deep concerns in the community in this regard. Tobacco smoking was also common.

All participants regarded alcohol as the most misused substance among those Aboriginal people who drank (it must be noted however that 90 % of Elders were reported as non-drinkers). One participant stated:

*...drink is promoted... it's seen as being the done thing. If you don't do it, you're socially unacceptable. Another said: drinking is just second nature to everybody up here.*

Another stated that 'there isn't entertainment in this town that doesn't involve alcohol', while another put it this way:

*...basically when they get paid, all their money's spent on alcohol, so it could be over 24 hours, it could be over 48 hours, then the rest of the week, they are trying to get money from wherever...*

Some participants gave a particular insight into the dilemma faced by those Aboriginal people who wished not to drink or take drugs, and as one participant said:

*I've interviewed quite a few ... Aboriginal people who tell me that when they make a choice not to drink or take drugs at all, they become subject to ridicule or enormous press, peer pressure, until they're actually coerced back into drinking. It's almost, they're treated suspiciously, and to a degree isolated by their peer group etc, and even by their own family. There seems to be an enormous amount of ... family pressure to drink - uncles, parents, other students...*

### ***Effect of substance misuse on carers and families***

Because of apparent confusion about areas in the town designated as 'dry' and 'wet' areas for drinking alcohol in Coober Pedy, some participants said there was more drinking in homes since this had been introduced and that this had led to more domestic violence, 'which leads into numerous other things':

*...the scenario of people coming down, relatives from the Land(s) specifically to drink and they've got a bit of money. That would be shared with the family household. So there'd be big drinking there. So the kids wouldn't be at school next day. Some of the people that perhaps got health problems get sicker. Damage is done. Maybe all the monies drank and the people have no way of getting back home. So, they're sitting there with no food and looking to all the services for support for food and sometimes bedding and certainly for fuel to get home.*

The health workers stated the effects of substance misuse on families extended to relationship problems with 'old girlfriends or boyfriends', accusations between people, especially at weekend drinking binges and parties, and child sexual abuse within families:

*...being aware of the abuse and not doing anything about it. Sort of close it into the family and isolate that kid or young adult...*

Drinking was considered to be a more overt problem for the Aboriginal community, where public drinking was common, as opposed to that in the non-Aboriginal community where it was 'kept behind closed doors'. One participant who was a doctor had worked in Coober Pedy for only a few months and was especially struck by, and sensitive to the high level of anger among his Aboriginal patients, compared to non-Aboriginal patients:

*My impression is, the main problem with alcohol use is ... they are angry. They are angry at themselves, and they are angry at me ... and actually without any reasons ... they are just angry.*

It was shared later in the conversation with non-Aboriginal providers that anger was apparent mostly in the age group between 20 and 40. It was felt these clients conveyed an attitude of 'you put us here, you made us this problem, you gave us this problem'.

This same participant saw Aboriginal people's style of drinking as dysfunctional and impacting in a major way on the family:

*...the person who drinks cannot function, cannot work, can't take care of his or her family. The whole family is deeply dysfunctional from the parents to the grandparents to the children. And also you can find families where the children drink at a very early age, (it) looks like they are looking up to these role models and following the parents. So it's a very, very big problem.*

Some participants also pointed out that when someone had spent all their money on alcohol, they would borrow money from someone else in the family, which could in turn increase family tensions and reduce already scant resources needed for such things as food, taking these away from other family members including children and women. There was no expansion on this issue in relation to the cultural tradition of group/family sharing, or how poverty, alcohol related brain damage or other dysfunction might also influence this behaviour.

#### ***Drug and alcohol services***

Participants reported that while there was an untrained Aboriginal substance misuse worker at Umoona, there were no specialist drug and alcohol services for the Coober Pedy community. There was no detoxification unit or dedicated beds at the hospital, and no sobering up services. A mobile



assistance service has now been set up. Visiting specialists and resident staff provide ad hoc counselling and support services. The closest specialist treatment facility for Aboriginal people needing rehabilitation was at least a day away by road. Clean needle and syringe facilities were an option that the hospital could consider, but were not provided at the time of the study. However there were plans for this to start at a later date.

Some references were made to the Coober Pedy Alcohol Strategy and developments that were underway or planned. It was possible to refer people with alcohol problems to rehabilitation centres away from Coober Pedy ('Archway' at Port Adelaide was mentioned as being good) and to the local FAYS for children and adolescents. Health workers in Coober Pedy offered general counselling, as was feasible within their time availability, experience and scope of practice. An added complication for Aboriginal workers is the likelihood of the client being a family member.

Some participants expressed their concern that in the past 12 months the hospital had refused to take people who were not sober. One worker described a situation where her client had been 'bashed up' and was 'drunk as well':

*I had a lady running over the hill and she was just dressed in a skimpy nightie. She'd been beaten about quite a bit. She was ... cut up on her face. She was an absolute mess. I rang the hospital and they said 'Oh you can't bring her up, you have to take her to the clinic, the doctor has to see her.'*

Because of the ensuing argument with the hospital, the worker said this client had declined treatment, reportedly saying: 'No, I don't want to go up there, if that's what they're like'.

This is a particular concern. It is standard practice in Australia, including South Australia, that all people who attend a hospital, and are apparently intoxicated, require an immediate medical examination to ensure there is no other medical crisis such as head injury, chest injury, stroke, severe infection or diabetes, or drug overdose. In addition, heavy drinkers are at risk of alcohol withdrawal, which in itself is a condition requiring timely medical investigation and hospital management for those at risk of complications.

These comments relate to the points raised earlier about 'institutional racism' in Coober Pedy.

## **Difficulties for people with mental health problems**

Medication and alcohol issues posed difficulties for people with mental health problems. One service provider commented: 'If it wasn't for the

health workers divvying up the medication, people probably wouldn't take them'. In one anecdote, a worker told of an older couple whose son 'obviously hadn't been taking his tablets' or had 'mixed them with drink'. The son was threatening to kill himself and his parents were very distressed to be told by the police, to whom they turned for assistance, '...there's really nothing we can do...'. The worker was worried that it seemed the son would have to do some harm before the police intervened.

A service provider related an incident of a family member who needed regular medication, including injections, to manage his mental health problem. Serious difficulties in managing his medication arose because he would move between Aboriginal communities and if he was without his medications would go 'off his head', saying that he did not have them with him or he had run out. In this case, there was a breakdown in the medication management and support system, and communication between health workers in these communities. In terms of alcohol use in combination with medication, another worker concluded:

*It's got to be monitored, if you're going to have them have some sort of normal, normality of life, because leaving it up to themselves, you don't know what they're going to do with their medication. And I've seen it happen that many times. Those people forgot to take it and it's usually on a weekend and they really go off the deep end.*

*Bringing Them Home* issues have an intergenerational impact, including Aboriginal people who live in the Coober Pedy area. Participants reported that awareness of this has increased awareness of the severity of difficulties for those affected, as told in an anecdote about a client who needed a regular injection for his mental health problem:

*...he came back searching for his mother ... (but) ... mother doesn't want to accept the fact that he exists. He was adopted out. Yeah, he keeps asking me ... all the questions that he should be addressing to his mother. I said I don't know anymore. The only person who can tell you how you came to be, where you are, where you fit in life is your mother. And if she's closed the door on you, you'll have to get on with your life as best you can. Stay on your medication.*

Legal issues could also pose problems. One worker described how one of her clients was sent to Port Augusta for a Court hearing and subsequently released into care, but:

*... (he was) just let go from the Court without the carer being notified, without having money to get back to Coober Pedy. Nothing ... that was quite ludicrous and anything could have happened...*

Other incidents were cited where as a result of court hearings in places other than Coober Pedy (for example, Adelaide or Port Augusta) it was difficult to

get people back home, and then they 'hang out' in these places and 'get into more strife'.

Another participant perceived Aboriginal people's social and emotional wellbeing difficulties as being largely to do with conflicts between themselves - not conflict with non-Aboriginal people:

*...they really don't get along well with each other. And from what they tell me when they're unhappy about their life, or their depression, it seems to come more from the fact that they've got all these family conflicts - extended family and ...other Aboriginal people ... that seems to preoccupy them most of the time.*

Children's self-esteem was reported as worryingly low:

*...the Aboriginal kids are virtually told, 'Well you're not going to get anywhere so there's no need for you to go to Year 12'. ...the kid's self esteem ... would you have it when you're told that right at the start?.*

One participant told of a thirteen year old Aboriginal boy who couldn't get past the letter A in the alphabet but knew the names of all the alcoholic spirits. He found this very sad. This comment led to a general discussion about the importance of education in the lives of Aboriginal children. One participant knew first hand of an instance (in another town) where most Aboriginal children did not return to class after lunch, but 'just went off and played'. This person had come to the conclusion that the problem was not one of lack of resources, but rather a problem of Aboriginal people not using resources appropriately - it even seemed 'they don't want to utilise them'.

This conversation led to further comments about the need to convey to Aboriginal people the message that 'it is OK to succeed and that there's nothing wrong with bettering yourself'. One participant reported that he had found there seemed to be 'a sense of shame' associated with success:

*... if you've got the first job in your family and you don't feel like you deserve it or you're afraid of how they're going to feel about you having that position ... it affects the whole community, it's almost like you're shunned...Without this message being conveyed: we'll never get change, and so everyone just falls back into the same old patterns of self-destructive behaviour.*

One of the participants summed up his interview by highlighting the one major question he believed ran across all health issues for Aboriginal people in Coober Pedy: *When are people going to be able to manage themselves?* Using the example of medication, he said the fact that health workers were 'running around doing it and organising it, paying for it and getting the stuff and everything else' only served to act as a crutch. The most important question then, is: *How do you get people out of crutch mode?* While this was

his view as a non-Aboriginal health professional, the complex historical and contemporary issues impacting on Aboriginal people perhaps makes this unrealistic for many, and also disregards the ways in which many Aboriginal people do manage, despite poverty, cultural dislocation, racism other adversities, as well as poor social and emotional wellbeing and physical health.

## **Postscript: Update on key events and contexts and Umoona Tjutagku Health Service**

Formal data collection for this report took place between March 2001 and July 2002. An analysis of the findings forms the bulk of this chapter. Many changes have taken place within the various health services in Coober Pedy since that time, including Umoona Tjutagku Health Service, and so this 'postscript' has been added to update the findings. This postscript was prepared by senior management of Umoona Tjutagku Health Service (Anne Vanajek, CEO and John Bouilly, consultant) in June 2003, and highlights the many changes and challenges to the Umoona health service. It also summarises the factors associated with the capability of Umoona Tjutagku Health Service to manage the provision of medication and other issues.

In June 2001, a medical practice available to the whole community (Indigenous and non-Indigenous) commenced work from the Umoona Tjutagku Health Service site. This general practitioner service, initially managed by the South Australian Centre for Rural and Remote Health (SACRRH), was funded by the Commonwealth Regional Health Service Program, and was designed to address the needs of the Coober Pedy Hospital and community for additional general practitioner services because of the inability, through illness, of a long-time resident GP to continue to services needed. In November 2002, the medical practice was re-located to the main street of Coober Pedy following a period of review, a planner's assessment and a decision to place the management responsibility for that practice with the Coober Pedy Hospital and Health Service. This meant that the doctors who had been working from the Umoona Tjutagku Health Service premises moved out. Umoona Tjutagku Health Service is now seeking funds to employ its own medical practitioner. Umoona Tjutagku Health Service's intention is to add a GP service to its team of nursing, Aboriginal health worker and administrative staff, and to provide a more comprehensive primary health and medical care service to its client community.

It is difficult to obtain and retain professional nursing staff in country areas and this is particularly so in remote towns such as Coober Pedy. Umoona Tjutagku Health Service has been fortunate in recruiting a registered nurse and an enrolled nurse to work in the clinic. Both employees are long-term locals, well known to the Aboriginal community. The nurses' appointment

has enabled Umoona Tjutagku Health Service to implement the Section 100 Scheme, a Commonwealth Department of Health and Ageing initiative, designed specifically for the provision of medication to those in need in rural and remote areas. Medication is supplied through a local GP's pharmacy and dispensed according to a doctor's prescription, placed in dosette boxes if required, then delivered by Aboriginal health workers. Because the medication is subsidised and therefore supplied without cost to clients, the availability of prescribed medication to our clients has increased significantly. Our organisation has welcomed this initiative and is appreciative of the service we are able to provide as a result of the scheme.

The dispensing of medicines is a painstaking affair and many staff hours are occupied in making referrals to GPs, checking the prescriptions, contacting GPs where instructions are vague, labelling with appropriate instructions and further reinforcing these instructions to the clients directly or through the assistance of the Aboriginal health workers. The ordering of medication, maintenance of supplies, the keeping of records and supervising the program are additional tasks for our nursing staff, made necessary by the fact that many Indigenous people suffer from chronic medical conditions requiring multiple medications on a daily basis. Webster or blister packs made available to clients would save some staff hours but problems are perceived, including time delays, there being no Webster packaging service available in Coober Pedy. Changes to prescribed medication would not be easy to manage if Webster packs were supplied from Port Augusta, and additional costs for transport and packaging would apply.

The service of traditional healers plays an important role in Aboriginal health through the maintenance of traditional approaches to healing and wellbeing. Although Umoona Tjutagku Health Service has no specific funding for traditional healing practitioner services, we endeavour to assist in this area. Funding is currently being sought from the Commonwealth Regional Health Service program for a three-year period and, if the application is successful, Umoona Tjutagku Health Service would be more able to provide traditional healing practitioner services to clients.

Environmental health and housing concerns need attention in the community. If the community is to develop and maintain a physically and mentally healthier population, the fundamentals of safe and clean housing, with operational electrical and plumbing services as well as basic furniture and cooking facilities are essential. Such facilities are basic requirements for better nutrition and better hygiene. Umoona Tjutagku Health Service hopes to receive Commonwealth Regional Health Service funding for the employment of staff to work with families in the home environment.

There is no safe housing for some community members who are well enough to be discharged from hospital but not well enough to return to community life. A type of 'step-down' or short-term accommodation unit in the community would be beneficial, and Umoona Tjutagku Health Service management is advocating for such a facility. An accommodation unit in the community would enable Umoona Tjutagku workers to visit, check clients' progress, administer medication and arrange for further supportive care as the need arises. It is difficult, if not impossible, for a full recovery to occur when clients do not have the basics of a bed (with blankets), proper food, clean clothes and warm surroundings.

Umoona Tjutagku Health Service has experienced numerous changes in the past few years and is still in a period of transition. A new building extension will soon be delivered to be positioned at the rear of the main building. This will allow reorganisation and improved ability to address client's various needs. Efforts are being made to obtain a full-time medical practitioner and additional staff for the Umoona Tjutagku Health Service, for it is acknowledged that an Aboriginal Health Service cannot fully meet the overwhelming health and medical needs of its population without the presence of a medical practitioner and staff to address the broad range of issues influencing the health status of the people.

Umoona Tjutagku Health Service has minimal staffing for the tasks it is asked to perform. The Umoona Tjutagku team is dedicated and sincere and perseveres in improving the health and wellbeing of its client population. Some positive changes have been noticed in some of its more difficult clients - those with complex health issues. This has been gratifying, because it has been the result of tolerance and a lot of hard work by the staff, over a prolonged period.

This quote from the CEO of Umoona Tjutagku Health Service, illustrates the commitment and aspirations of the service.

*We are aware that if we are to make positive changes to health issues through management, education, and the prevention of disease, we must first gain the trust of the people. This is an essential ingredient of a positive relationship between clients and workers. We believe that, with a little extra financial commitment from government, we will be able to add capacity to our organisation so that the efforts of our staff will make a real difference to the lives of the people we service. Although we face many challenges, we believe that the future holds more promise of a happier and healthier future for the Aboriginal people of Coober Pedy.*

Members of the research team visited Coober Pedy in June 2003 and met with key stakeholders from Aboriginal and mainstream services. Sadly, this visit confirmed the findings drawn from data collected two years earlier. We

witnessed a divided and disadvantaged town struggling with poverty, lack of opportunity and isolation. Racist attitudes remain very evident. Many Aboriginal families are living in appalling circumstances, coping with chronic physical and mental health problems including alcohol or drug use problems, but with inadequate health and social supports. There are still barriers to accessing mainstream services. For example, we noted that Aboriginal people are still being sent away from the hospital without being assessed despite serious illness and risk. Another new barrier that actively discourages Aboriginal people from going to the hospital's accident and emergency department is the requested 'donation'.

## Discussion and recommendations

This project explored issues, contexts and needs affecting safe medication management by Aboriginal people with mental health problems and their carers in the Coober Pedy region. From the findings, three broad themes were identified:

1. Securing reliable, accessible, affordable and culturally appropriate mental health and alcohol/drug services locally.
2. Improving the safe management of medications within an Aboriginal context.
3. Better utilising health and other human services in Coober Pedy.

These three themes and associated recommendations specifically address the research problem in practical and useful ways. They provide insight into factors leading to the problem and pathways out of the problem to a brighter future. The analysis of data clearly shows Aboriginal people in Coober Pedy have both mental health problems and medication management problems. We do not believe these are insurmountable. Indeed our recommendations arise directly from the research participants themselves in many instances. We request the recommendations be read in conjunction with the data analysis and findings - there are many useful insights to be gained beyond the wording of the recommendations.

A strong current running through all three themes is 'taking responsibility'. Both Aboriginal and non-Aboriginal participants conveyed the powerful message that Aboriginal people want to be more self-reliant and exercise more control in their lives. It was understood that this will require capacity-building and empowerment. As researchers, we have taken this message on board and used it as the central pivot of our discussion and recommendations. It can be considered our philosophy or central belief that Aboriginal people in Coober Pedy can experience more self-directed management of their mental health problems and their medications, providing they are supported by non-racist, adequate, accessible and culturally safe services and practices. Becoming more self-reliant is a 'whole

of community' and inter-generational challenge requiring all non-Aboriginal and Aboriginal leaders and services to work together to ensure that much needed education, employment, cultural safety and related aspects are in place to support growing self sufficiency. At the same time, it is accepted that there will continue to be limits to what can be achieved amongst severely ill or disabled Aboriginal people such as the older people who are incapacitated, and will continue to need regular assistance with every day living and health care.

Consultation with the Aboriginal community Elders may well give insights into how best to 'move forward' with the issues above, recognising that it is these Elders who have the knowledge of how best to assist their people, as it is they who are carrying the enormous load in caring for family, including young children, while being frail and sick themselves - they are the 'backbone' of their community. There are new health initiatives now under way in Coober Pedy and we are confident the outcomes of this research can contribute to further positive development.

*Special note:* Since the time of data collection for this project, the Umoona Tjutagku Health Service has developed Strategic and Business Plans [16, 17]. These Plans address some of the same issues as this project and should be considered in conjunction with this report. For example, the plans address honouring the cultural context and expansion of health services.

## **Securing an accessible, affordable and culturally appropriate mental health service**

In this project, there was an overriding, across the board consensus that Coober Pedy requires a full-time Aboriginal mental health service. Mental health problems, or issues concerning social and emotional wellbeing surfaced clearly as the root cause of most Aboriginal health issues - whether related to medication, drugs and alcohol, or acute or chronic illness. Yet, at the time of the project, there was no permanent provision for mental health personnel either at the hospital or Umoona Tjutagku Health Service. One mental health nurse, seconded from the Whyalla hospital for a minimum two days a fortnight, was reportedly the only mental health specialist for the whole community. Local general practitioners had some incidental expertise and offered a service as/when possible as a stop-gap.

Alcohol misuse loomed as the issue of greatest mental health concern. Aboriginal people who drank to excess caused immense emotional, psychological and physical damage to themselves and those around them, especially immediate and extended family members. This damage was both direct, such as violent behaviour within the home, and indirect, such as all available monies being used each week to binge drink, leaving no money for



food or other family essentials. The Coober Pedy Alcohol Strategy is evidence of the State Government's concern and commitment to address harmful alcohol use in public places and its associated problems in the town. Project participants did not speak at any length about this ongoing Strategy, but it was evident that few of its strategies had been implemented at the time of writing and that its comprehensive goals (as stated in the Introduction) must be pursued vigorously.

Considering Aboriginal mental health problems within the broader context of social and emotional wellbeing (incorporating lifestyle, family, community and cultural factors), project findings suggest very few Aboriginal people in Coober Pedy are problem free. That is, it appears likely that all Aboriginal people suffer some degree of 'mental upheaval and imbalance' - to use one participant's preferred term for psychiatric diagnoses. This, taken together with the fact that for Aboriginal people, social and emotional wellbeing factors pervade all aspects of their lives, suggests a culturally appropriate mental health service is of paramount importance.

*The Mental Health Plan - Northern and Far Western Region 2001 - 2004* appears to have had little impact, despite its recommendations for Coober Pedy. None of the participants mentioned their knowledge of this strategy, which may suggest lack of engagement or consultation with local Aboriginal community leaders or service providers.

#### Recommendations

- Provide a full-time health service for Aboriginal people in Coober Pedy that is culturally appropriate and adequately staffed with Aboriginal and non-Aboriginal people, including mental health and alcohol/drug specialists.
- Address the capacity of Umoona Tjutagku and mainstream services in Coober Pedy to deliver quality holistic care to Aboriginal clients.
- Ensure that all general health professionals have basic mental health and alcohol/drug skills.
- Strengthen links between the mainstream mental health team, Umoona Tjutagku Health Service and other service providers, and clarify roles and responsibilities.
- Provide a step down facility in Coober Pedy for Aboriginal people discharged from hospital but not yet well enough to go home.
- Continue to implement and evaluate the Coober Pedy Alcohol Strategy, and ensure that it is not further marginalising Aboriginal people at risk.
- Follow up actions (if any) arising from the *Mental Health Plan - Northern and Far Western Region 2001 - 2004*.
- Encourage senior management of SA Mental Health Services to consult effectively with Aboriginal leaders and service providers in Coober Pedy.

- Involve all mental health and alcohol/drug workers at Umoona Tjutagku Health Service with the ongoing implementation of its Strategic and Business Plans, and further development of the Service.
- Provide social and emotional wellbeing education and active support to Aboriginal children, adolescents and adults.
- Ensure that the mental health service for Aboriginal people in Coober Pedy enables clients to include traditional healing approaches in their care plans, if they wish.
- Provide education for clients, families and workers about health matters and the various systems/modes of health care, enabling informed choice and advice.

## **Improving the management of medications within an Aboriginal context**

In Coober Pedy, many Aboriginal Elders take prescribed medications, often for chronic medical conditions such as diabetes and renal disease. Younger Aboriginal people also suffer from chronic medical conditions, as well as acute respiratory and other illnesses for which they take medications such as antibiotics. Painkillers are commonly required after accidents and injury, and are also often sought by some Aboriginal people for a range of purposes unrelated to pain. Drugs are prescribed for various mental conditions and complaints, including Alzheimer's disease. Overall, medications seem to play quite a large role in the lives of Aboriginal people in Coober Pedy, though many may not use medicines as prescribed due to poor knowledge or opportunity, and/or poverty.

Recognition of the importance of medication can be seen in the various processes designed to ensure Aboriginal people actually take their medications as ordered. These processes are partly driven by there being no resident pharmacist in Coober Pedy for the past fifteen years. At the time of data collection, prescriptions were faxed to Adelaide or Port Augusta and the medications delivered back to Coober Pedy. A registered nurse at the hospital placed the medications in dosette boxes according to doctors' orders and the medications were then delivered to clients during the week by Aboriginal health workers as required, or at weekends by community health staff. If clients were unable to pay for their medications, deductions from Centrelink payments could occasionally be arranged, but we were told that often Umoona staff paid for needy clients' medicines from their own pockets, especially for those without Medicare or health care cards, so that clients would not go without lifesaving medicine. These processes required close liaison between health providers from the hospital, doctors' clinics and Umoona Tjutagku Health Service. They amounted to a supportive medication service, although few of these workers had had any training in safe medication management.

It is notable that since the time of data collection, there have been some developments in relation to pharmacy dispensing arrangements in Coober Pedy. Currently two resident doctors provide a pharmacy service in Coober Pedy, however this relies on the goodwill of those medical practitioners and partners who run the pharmacy. Also, Umoona Tjutagku is now eligible to dispense certain medicines under S100 legislation. Umoona has a limited supply of essential medicines on site, a registered nurse employed by Umoona makes up dosettes according to doctor's prescriptions and health workers distribute medications to clients as needed. Clients need not pay for these medicines. Umoona buys the medicines at PBS reimbursement costs. This application of S100 arrangements has benefited Coober Pedy's Aboriginal clients greatly - with more people actually receiving and taking their medicines.

Despite assistance from health workers delivering medications to Aboriginal clients, serious problems remain. One such problem is that many people do not take their medications as prescribed, thus further jeopardising their health and wellbeing. Reasons include: not understanding or being unable to read instructions on labels or pamphlets; not understanding specified timeframes for administration; not understanding repeat prescriptions; forgetting to take them; losing them; not wanting to take them because they are feeling better; not wanting to take them because they are not 'doing any good'; not understanding or agreeing with the doctor's advice; not having them nearby when visiting or moving between locations; not being at home when they are delivered; inability to manage the dosette box; distraction from taking them due to other responsibilities and domestic upheavals; ill-informed advice from friends and family, and possibly untrained workers as to whether, how or when they should be taken; not having any to hand because they have been lost, swapped, traded, or sold; 'running out'; not having appropriate storage facilities; conflicting beliefs between traditional and non-Aboriginal medicine; and in particular, experiencing complex daily life issues that mean people relegate their personal health as a lower priority in favour of caring for others - this is particularly pertinent for older women.

Our research suggests the problem of non-compliance may be compounded by Aboriginal clients not valuing medication use due to traditional beliefs, negative experiences with non-Aboriginal health professionals, lack of education, and/or because they have little opportunity to play an active role in negotiating their health care decisions. Findings also point to a significant cultural reason as to why many Aboriginal clients do not comply with their medication regime, in that 'western' disease diagnoses and treatments, including medications, are irrelevant to traditional understandings of health and disease. Aboriginal people's priorities may be different, at times to the point of not paying attention to an illness that could be life-threatening if

medical treatment is not followed, and this is a major dilemma for non-Aboriginal health professionals whose goal is to provide medical treatment.

Misuse of alcohol further compounds the issue of not engaging in essential medical treatment and medication use. Many preventable complications and deaths could be avoided if Aboriginal and non-Aboriginal groups could work together to provide access to culturally safe services that can address issues associated with various diseases, as well as alcohol withdrawal, comorbidity and other poor outcomes such as trauma through violence, incarceration or death. Participants have some understanding of the complexity of the medication compliance issue, and suggested that attitudes and behaviour change could occur through education.

#### Recommendations

- Continue to support Umoona Tjutagku Health Service in its provision of essential medication to needy Aboriginal clients through the Commonwealth funded S100 scheme. Monitor and evaluate the developments regarding the S100 scheme in other remote regions of Australia and be aware of others' experiences and possible pitfalls.
- Secure a resident pharmacist in Coober Pedy to serve the town and surrounding areas.
- Commence immediate long range planning to improve the design and labelling of dosette boxes, and explore other options such as Webster packs or bubble packs.
- Provide community education about safe medication management.
- Ensure that medication services for Aboriginal people in Coober Pedy offer a continuum of support appropriate to those wishing to use traditional healing practices as well as, or instead of 'western' medicine.

### **Better utilising current health services in Coober Pedy**

Apart from a severe lack of mental health, alcohol and drug, pharmacy and maternity services, the Coober Pedy community as a whole is relatively well catered for by a range of health professionals, although staff turnover is high (since 2001 to the end of 2002, there were three different Directors of Nursing and multiple changes in nursing staff in the hospital, as well as many staff changes in Umoona Tjutagku Health Service), making the smooth running of services difficult and continuity of care less than optimum. In fact at the time of our data collection there was no doctor or registered nurse at Umoona Tjutagku Health Service, leaving Aboriginal people with few choices as to where they received general medical care for chronic or acute health problems. This situation has only recently been eased. In addition, specialist medical and/or nursing services have only been available periodically at the hospital by advance appointment, requiring forward

planning by staff and clients. This situation cannot facilitate 'on-the-spot' emergency care or timely monitoring by specialists for those with serious health problems, including mental health disorders and addictions. In addition to the hospital and two general practices, Aboriginal people could access health care for less serious or acute illnesses through the Umoona Tjutagku Health Service. Within this community controlled Aboriginal health service, Aboriginal health workers have provided various health-related supports. These services aim to provide culturally appropriate assistance to Aboriginal people (for example, banking, bill paying, and correspondence and phone calls in relation to Aboriginal rights issues) as well as medication management, health screening and monitoring, and education.

Coober Pedy is a small and unique opal-mining town in remote and arid South Australia, populated with people from diverse cultures as well as local and visiting Aboriginal people. There is a continuing need for a sufficient number of well qualified general health professionals whose services are augmented by adequate provision of specialists, in particular mental health and alcohol/drug professionals, all of whom are needed by the Aboriginal community.

As one would expect, given the poor health status of Indigenous Australians, our study has found that Aboriginal people in Coober Pedy are regular users of local mainstream health services and their own Aboriginal service. Older Aboriginal people living in the Elders camp on the outskirts of the township require considerable assistance, especially travelling to and from services in the town, getting their medicines and doing their food and other shopping. Assistance is needed by mothers, grandmothers and other family members who have difficulty getting to the general practitioner or accessing timely specialist appointments for their children. Many people require help with running their homes, and acquiring and maintaining basic commodities for daily living such as furniture and bedding, clean water, heating and cooling, clothing and other essentials, all of which impact on their poor health status. Occupants almost always include sick family members who require extra care, resources and support. Family and friends passing through and visiting from the northern Anangu Pitjantjatjara Lands, for example, add further pressure on local households. Coping with the consequences of alcohol misuse is a constant factor, as is the need for adequate food and transport.

Both Aboriginal and non-Aboriginal service providers were unhappy with aspects of health care for, and utilisation by Aboriginal people. One doctor was particularly concerned that, in his opinion, Aboriginal people were using the hospital's accident and emergency department inappropriately as an all-hours consulting service, with Aboriginal clients insisting that they

will stay until they see the doctor, making their management difficult when refused. This may have been due to a number of factors such as no alternative service available after hours, and/or hospital staff not understanding the impact the harsh environment had on people who had to walk to town and the hospital, thus choosing not to travel during the day in extreme heat, especially when ill or injured, and thus asking for health care after hours. It is notable that having access to after hours medical care is a service that other people living in larger towns and cities expect and have access to 24 hours a day. People under the influence of alcohol and/or other drugs who attend the hospital should receive particular attention due to their added risk of medical complications through injury, particularly head injury and concurrent illness. This does increase the complexity of providing adequate health care in the context of scarce resources, and perhaps lack of knowledge about the medical risks related to intoxication and other alcohol/drug related conditions.

Concern was also expressed by Aboriginal and non-Aboriginal providers that the hospital was at times used as a means of getting free accommodation and meals by some Aboriginal people, who would seek to be admitted under the pretext of illness because they had no money or a safe place to stay.

The Aboriginal health workers and service providers were particularly concerned with those clients who did not keep their appointments and were not punctual. This was apparent especially with doctors' appointments, to the point where one doctor was withdrawing services for Aboriginal people because of disruption to his practice. It seems Aboriginal people relied heavily on being transported to wherever they needed to go - with perhaps an assumption that they had not anticipated what needed to be planned for or what they needed to do themselves, rather than wait for something to happen and then being unable to attend.

A similar issue prevailed with the medication services. If the Aboriginal health workers do not seek out their Aboriginal clients and personally administer the medications or remind the clients to take them, they would likely not be taken. It is apparent many Aboriginal people have a poor understanding of their health problems and the role of medication in their treatment. Consequently, they may not understand the need for their medication-related services - including how their medications need to be safely procured, stored, administered and renewed. Our research highlighted significant cultural and environmental factors involved with this. 'Western' diagnoses and treatments are often not a top priority (compared with, for example, Aboriginal family and relationship issues) and can simply fall away in importance and reason for action. Aboriginal people have indicated that they want to be healthy and happy, and need culturally safe health services.

Our research suggests the highly regulated/supervised nature of the mainstream health services available to Aboriginal people in Coober Pedy may contribute to the problem of these services not being perceived as friendly or accessible, and therefore are less valued and perhaps used inappropriately by some Aboriginal people. Both Aboriginal and non-Aboriginal participants in the project were alert to the risks of them 'taking over' responsibility for their clients' health, but knew from their experience that if they did not provide particular services such as transport or administering medication, nothing happened. It is a 'catch 22' situation, compounded by poverty, cultural distress, incremental and inter-generational grief and loss, comorbidity of serious and chronic illnesses, mental health and alcohol/drug problems, poor nutrition and unhealthy/inadequate living conditions, and emotional trauma arising from an historical legacy of colonisation, dispossession and racism. Even so, what is important for Aboriginal people with social and emotional wellbeing problems, as one participant put it, is for them 'to take control of the way they think, and the way they react, rather than be the victim'. Or, as put very aptly by an Aboriginal participant, what's most important is 'being responsible for your own life really, ultimately'.

Of particular concern were reports of Aboriginal people receiving a lesser level of care within the mainstream services (hospital and doctors' clinics) because of their Aboriginality, the relationship of this to culturally inappropriate health care practices and for many, the experience of racism in their daily lives. . Research participants especially asked for strategies from this research to address these racism issues.

#### Recommendations

- Urgently develop strategies to recognise and eliminate racism in all its forms - overt, covert, individual and institutional.
- Establish an Aboriginal community shop selling fresh, cheap, accessible and wholesome food, building on the experience of similar shops elsewhere.
- Ensure that all persons who attend the hospital accident and emergency department are properly assessed, regardless of their race, and including people who may be intoxicated.
- Promote ongoing dialogue between Aboriginal and non-Aboriginal health providers about increasing access to, and cultural safety of services.
- Develop strategies for increasing Aboriginal people's responsibility for their health, taking account of the limited services currently offered.
- Provide a free community bus for Coober Pedy.
- Provide essential public infrastructure in Coober Pedy including public telephones, another drinking water fountain, toilet and bathing facilities for families, and ensure they are accessible to Aboriginal people, supervised and well maintained.

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# Attachment 4

## Report on research conducted in the Riverland

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**This report was prepared by:**

- Anita De Bellis
- Inge Kowanko

**Also involved in this project were:**

- <sup>a</sup> Charlotte de Crespigny, Helen Murray and Mike Turner from Flinders University
- <sup>a</sup> Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council

The research team had initial contact with Kanggi Yuntiwarrin Aboriginal Health Service in Berri. A research team member visited this organisation a number of times explaining the project, and an Aboriginal research assistant acceptable to the local community was recruited and trained. One focus group with Aboriginal health workers and community members, one interview with an Aboriginal person with a mental health problem, one regional steering committee meeting of Aboriginal health workers and mainstream health professionals, and one interview with an Aboriginal health worker were undertaken. All who were involved with the project through these meetings and interviews were enthusiastic and willing to participate in this research, which they viewed as worthwhile and needed. Unfortunately, due to various circumstances, Kanggi Yuntiwarrin was unable to continue participation in the research.

The data that was collected and analysed highlighted similar problems and themes to other regions that had participated in this SA-wide research. The interview with the Aboriginal person with a mental health problem emphasised problems associated with comorbidity and the use of medications. This person was taken from his family, abused physically, emotionally and sexually, and has spent his life since 9 years of age on anti-psychotic and tranquilising medications, alcohol and other drugs. This person described his life as 'lonely and dark' and 'I'd rather be dead than live in your stinkin' fucked up world'. He had been prescribed many medications in his life but had no knowledge of them other than their name, how they made him feel, his agitation when he did not take them and his consequential turning to other available drugs.

The focus group with Aboriginal health workers and community members highlighted the inherent problems of Aboriginal health as well as those specific to medication management and mental health. The multivariate nature of the problems within the Aboriginal health care system has again been made apparent through this focus group. The following was stated, highlighting that:

- medications are given out too freely by doctors;
- there was a poor quality of health services for Aboriginal people;
- the cost of medications was exclusive and the way the Aboriginal people handle their money was different;
- multiple medication use of some community members (up to fifteen tablets at a time, eighteen tablets a day) was evident;
- there be resources for some sort of pharmaceutical fund for Aboriginal people;
- there is a need for further education of Aboriginal health workers;
- there is a need for holistic and coordinated care;
- the existence of drug problems among young Aboriginals was apparent;
- there was a presence of institutionalised racism;
- there was a high unemployment rate;
- there was a need for more resources for Aboriginal health and Aboriginal health workers;
- a more coordinated service was needed for caring for the elderly Aboriginal people;
- transport and accommodation was a major problem because of dispersion of services between the towns and the city;
- there was a lack of dental services available;
- there was overcrowding and homelessness in the communities;
- there were problems with different brands of medications and their relevant costs;
- there are feelings of being used as guinea pigs by doctors for medications;
- unintentional overdoses were apparent;
- there was a preclusive expense in buying or hiring inhaler machines (nebulisers); and
- there was a lack of transport and, therefore, access to doctors for older people in outer communities.

The interview with the Aboriginal health worker also emphasised some of the above points, as well as the importance of the traditional healing practitioners and the fact that there was no access in the region. Other points raised were the smoking of yarndi (marijuana) by the young people and whether this was a good or bad thing, the violence in the community underpinned by racism, the lack of pharmacy services, the problem of blister packs looking like lollies, and the problem of illiteracy among Aboriginal people and how this affects their medication management.

Although the research activities in the region were limited, this does not diminish the grave problems that the Riverland region and its communities are facing in regard to Aboriginal health in general, and medication management and mental health specifically. The Aboriginal health organisation was in crisis at the time but will still benefit in the future from the overall recommendations emanating from this SA-wide research report on which local and regional action can be based. The issues uncovered by our work in this region, along with the findings of our research in other SA regions and other data collected in this project, are being considered by the Statewide steering committee in drafting the final recommendations. Representatives of Kanggi Yuntiwarrin were invited to participate in this process.

# Attachment 5

## Report on research conducted in the Murray Bridge region

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**This report was prepared by:**

- Anita De Bellis

**Also involved in this project were:**

- Charlotte de Crespigny, Inge Kowanko, Helen Murray and Mike Turner from Flinders University
- Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council (SA) Inc.

Collaboration with the Aboriginal community began in this region through initial contact with the Aboriginal Liaison Officer attached to the Murray Bridge Hospital and a meeting of two researchers with three Aboriginal persons who were health workers associated with the Kalparrin Aboriginal Community. A member of the research team visited the Aboriginal Liaison Officer. A further interview was conducted with an Aboriginal health worker

The overall project was explained and advice was sought as to the best way participation by the Aboriginal community in the Statewide project could move forward for this region. As a result of this meeting, a member of the research team was invited to a forum in which the region's Indigenous health workers came together for a regular meeting and to provide support to each other. The members of this forum included health care workers, social and emotional wellbeing team members, Elders, community members, mental health workers, and alcohol and other drug workers. The meeting was arranged to: explain the project and its aims and methodologies; discuss the issues already apparent in other regions; invite participation; and disseminate information.

A member of the research team attended the next available forum date. A total of 14 Indigenous health workers were present and represented the entire region. Following individual introductions, the research team member presented the project to the forum. This presentation included an overall explanation of the project, the collaboration, guidance and direction of the Aboriginal community in the success of the project, the types of data collection that were being used, ethical considerations that had arisen, and

ownership of the data and project. The pilot study conducted in Northern Metropolitan Adelaide through Muna Paiendi was also presented to this group. A copy of the survey form was tabled and information was given about how this was presently being administered statewide. A number of the workers had already been contacted regarding the survey and they were further encouraged to participate by completing and returning it. Much discussion and questioning took place in a lively and open forum.

Those who were present at the meetings and the interview spoke about very real problems faced by their communities and individuals they knew in relation to medication management. The historical context of Aboriginal health was highlighted in all meetings through story telling. All participants had a story, anecdotes and examples that highlighted problems specific to the research being conducted. Discussion centred around social and emotional wellbeing, and the enormous mental health problems and trauma suffered by their community. All exhibited very deep wounds and emotional scars that are affecting the social and emotional wellbeing of Aboriginal people, including: past treatment; the constant deaths within families; the constant grieving; the loss of culture and meaning for their people; the consumption of alcohol and other drugs; the loss of Aboriginal manhood; barriers to land title; and a serious general disconnectedness.

Stories were told of individual cases that highlighted the Aboriginal health workers' limited knowledge around prescribed medications, inadequate access to medications, reluctance of visiting doctors for prescribing medications, cost of medications and misuse and abuse of medications, as well as alcohol and other drug consumption. Mental health problems were explicitly apparent in all the stories. Transport was a large issue and often was the determining factor in whether or not there was compliance. The need for more resources, the employment of Aboriginal health workers and improving their education and training were viewed as imperative in order to make a difference to the situation. It was stated that Aboriginal clients have a lot of difficulty understanding what doctors say to them about their medications and that there is no 24-hour service that can help when there are problems for families.

In regard to participating in the project through focus groups and interviews with Aboriginal people, concerns were raised about ethical, privacy and confidentiality issues. All the participants were reassured in regard to these matters to the satisfaction of all present.

At the conclusion of the forum, there was a consensus of participation on behalf of the Indigenous community in what was seen as a worthwhile and important project. Participation was enthusiastic and arrangements were made to get the project moving and the Indigenous community involved.

It was agreed that a focus group would occur during a workshop day that was already in the planning and was to be held in two months time, and that the Aboriginal Liaison Officer would contact the research team. Most of those present agreed to set up individual interviews with Aboriginal persons with mental health disorders or their carers, and indicated they would contact the research team when any potential participants had agreed to an interview or focus group.

Although members of the forum expressed willingness to participate and were enthusiastic about the perceived value of the project, both time and resources were limited. Unfortunately, the research project timeframe lapsed before this regional community was able to participate. The research team was not advised of the focus group and workshop day being organised or of any individual interviews that could be conducted within the project's timeframe. The research at this stage was drawing to a completion and it was with regret that the Murray Bridge region was unable to participate through further data collection. It was, however, very strongly reinforced that this region had generic problems similar to other regions - problems associated with medication management and mental health disorders - and it is hoped the Indigenous community in this region will benefit from the outcomes of the overall project.

The issues uncovered by our work in this region, along with the findings of our research in other SA regions and other data collected in this project, are being considered by the Statewide steering committee in drafting the final recommendations. Key stakeholders from the region have been invited to participate in this process.

# Attachment 6

## Report on research conducted in the metropolitan Adelaide region

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### **This report was prepared by:**

- Mette Groenkjaer
- Inge Kowanko
- Charlotte de Crespigny
- Helen Murray

### **Also involved in this project were:**

- Anita De Bellis and Mike Turner from Flinders University
- Scott Wilson and Warren Parfoot from the Aboriginal Drug and Alcohol Council

## Acknowledgements

The project team acknowledges the generosity of the Aboriginal clients, carers, health workers and other people who shared their stories and insights. These participants cannot be named for confidentiality reasons, but their individual contributions are very much appreciated. The project was supported by a grant from the Quality Use of Medicines Evaluation Program through the Commonwealth Department of Health and Aged Care.

## Introduction

The research team had already conducted a pilot study [1] for this project with Muna Paiendi Aboriginal Health Service in the Northern Metropolitan region of Adelaide. The pilot allowed us to develop and refine our research approach and methods for use in the SA-wide project *Better medication management for Aboriginal people with mental health disorders and their carers*. The pilot study provided a rich insight into the experiences and views of Aboriginal people with mental health disorders, their carers and health workers in relation to medication use. The pilot study highlighted that medications are not always used safely or optimally, potentially putting people at risk. It showed that many Aboriginal people with mental health disorders, their carers and other family members are struggling to cope with multiple and complex problems in their lives, and are not always receiving adequate or appropriate support. The major issues related to: poverty; shame; understanding of mental illness and medications; coordination of

services; access to adequate and culturally appropriate services; the relationship between alcohol or other drugs and mental illness; and the burden on carers. The pilot study has allowed us to explore these emerging issues further in the statewide project, consistent with our action research approach. The report of the pilot study [1] (Attachment 8) includes recommendations and has already been influential in modifying policy and practice (see below and Chapter 8).

In this paper we report on the component of the SA-wide project conducted in the metropolitan area of Adelaide. This includes analysis of interviews with Aboriginal people with mental health problems, carers and other family members, and workers who provide them with health and related services. We also comment on early outcomes and future plans arising from both this work and the pilot study in the Metropolitan Adelaide region.

## **Participants and methods**

The research project involvement in this region was ultimately less than we had originally planned. Multiple demands on the limited personnel, resources and time of the various metropolitan Aboriginal health and related services, as well as pressures within the research team, meant that a local host organisation was not arranged and a local steering committee was not formed. However, the research team initiated and maintained communication with key stakeholders in Aboriginal and mainstream organisations, and invited them onto the Statewide steering committee.

We negotiated with a number of organisations to recruit interview participants who were eventually sourced from Kura Yerlo, Aboriginal Prisoner Support Service, Taoundi College and Westcare. A semi-structured interview guide (see Chapter 5) and thematic analysis of interview transcripts were used to explore issues and experiences impacting on medication use by Aboriginal people with mental health problems and their carers. Aboriginal and non-Aboriginal researchers conducted the interviews.

Eleven interviews were conducted in the Metropolitan Adelaide region. Seven one-to-one interviews were with Aboriginal individuals who were, or had been carers, or who had physical and/or social and emotional wellbeing problems themselves. Another interview was with a person employed by the Aboriginal Prisoner Support Services. Two focus group interviews were held with 6 male Aboriginal Elders and 12 Elder Aboriginal women (most of whom were carers). Other data included reflections of a member of the research team after talking with a group of 22 Aboriginal Elders at a college in the Adelaide metropolitan area. Also included as data was another group discussion with 11 participants, where preliminary findings of the first interviews were presented, discussed and elaborated on, thus enhancing the study's validity, credibility and trustworthiness.



## **Findings**

### **Demographics**

The participants' ages ranged from 56 to 72 years. All were Aboriginal community members. All participants had experience of: social and emotional distress resulting from lifelong social dislocation, grief and loss; diagnosed mental health disorders; substance use problems; or other physical health problems, personally and/or as carers of family or community members living with such challenges.

Most had lived in Adelaide all their lives, with others originating from country areas or interstate. Accommodation types varied from units to houses and some had support from the Housing Trust. Eight different Aboriginal language groups were mentioned.

Education levels varied from having no schooling at all to completing a traineeship, and one person was studying at the time of the interview. Participants' employment histories also varied and included labouring, hospitality work and health care. One person had never worked for pay. Most participants currently received a pension or allowance of some kind. Several mentioned how difficult it was to make ends meet on such a low income. To receive her pension as a carer, one woman was unable to work, even though she would have liked a job. Another person who cared for a teenage relative was living on her own disability pension and child endowment. The participant from the Aboriginal Prison Support Service worked in a house for clients who were either coming in or out of the prison system.

### **Use of health care and other services**

Participants had complex health problems and used several health and other services, both Aboriginal and mainstream. Participants talked about these services being multicultural and most expressed satisfaction with them.

They visited general practitioners and nurses in their local suburbs, and some had visited the same general practitioner (GP) for years. They used Aboriginal Home Care, Domiciliary Care, Centrelink, the medical centre at Kura Yerlo at Largs Bay, and Nunkuwarrin Yunti Aboriginal health service in central Adelaide. One woman found Centrelink confusing and wanted more Aboriginal people to work in such services. One participant preferred not to use Nunkuwarrin Yunti because of perceived lack of confidentiality. Another participant with a physical disability was satisfied with the health services he used, and told how his doctor would call and remind him when it was time for a new appointment, but that he was not yet receiving any home help despite being in a wheelchair. Aboriginal health workers were much valued by several participants for their intensive help and practical support.

One carer of a chronically ill child used the Women's and Children's Hospital. Another participant was given occasional respite care in hospital. Some used community health services (e.g. The Parks) and suburban clinics for physiotherapy and diabetes monitoring. Others talked of visiting specialist services in the suburbs (e.g. ophthalmologist, podiatrist, aqua-therapy). Most participants used such services every two to four weeks or more frequently if they were ill. Participants also mentioned that they could access fitness groups, carers' groups and Elders groups. One participant was aware of these groups but was not interested in socialising outside the family.

However, some participants told how they did not always receive the health care and support they needed from services. Most criticism was directed at the major hospitals, and the following experience related by a client and her carer (P#10) is just one example of similar stories collected during this project. A woman with severe anxiety and depression had to go to hospital for emergency mental health care, and was 'bumped around' from the Royal Adelaide Hospital to the Queen Elizabeth Hospital and finally to Glenside Hospital. During this time she was seen by five different psychiatrists and never saw the same psychiatrist more than twice, so that 'they did not ever get past the first page' of her history. It was reported that she had been discharged from Glenside Hospital without medication, script, referral or transport options, and without being assessed by a doctor prior to the discharge. Additionally, the hospitals failed to liaise with the Aboriginal Health Workers for follow-up care, and the woman had to arrange that herself via Westcare. It became apparent that there was a lack of cooperation between the three different hospitals in this case. The woman's experiences were further put into perspective when her carer said:

*I don't understand how someone can get better being doped up like that and plus, how can you relate your problems to a psychiatrist when they've got you drugged up and she was. She was heavily medicated. And then the psychiatrist gave her 5 minutes once a...a fortnight. I think it was once a fortnight. She had to beg them to see the psychiatrist. She...she would. The few times I went up there, she went off. She was going off. Just losing her head at people in there because no one were listening to her and the social workers even, she couldn't get to see them (P#10).*

The woman was disillusioned with health services and said:

*I don't want to go to the system. It's failed me dramatically and I don't like the way they look down on you. On, you know, oh here comes another one who's got issues. It's...It's...it's awful the way they treat you (P#10).*

Other participants voiced similar sentiments, and told their experiences of inadequate and inappropriate service provision. Queen Elizabeth Hospital was mentioned in another case where staff showed cultural insensitivity.

The carer said:

*They didn't understand his cultural needs. And sometimes you get a bit peeved with them because they don't understand but that was an issue and I'm not sure what the hospital does about looking after the cultural needs of people from different backgrounds. Whether they in-service staff or what. They need to (Elder Women's group).*

One participant with several health problems was disappointed with Wesley Mission, which offers a variety of home care 'packages' to Aboriginal clients. Despite accepting their offer, this participant has been waiting several months without hearing from them. We were also told that this organisation normally paid for a massage for her arthritis but had stopped refunding the fee because of a cost increase. Moreover, this woman had received a letter from Wesley Mission apparently charging for services she did not receive. The participant was very frustrated about this and the interviewer agreed to sort out the matter for her. This woman used Western Domiciliary Care instead and was satisfied with this service. She said:

*Whether it's Dom Care or respite or needs with service goods, the Dom Care's always been there, it's always done their best for me you know... Home Care has its bellyaches but you could always talk to them fellas in Home Care, but they let you know what it's all about. But these fellas with Wesley House, it's like um, they want to, they want you, they want you in their service but it's at a cost? (P#3).*

Transport to health services was not a problem for most participants. Some could easily walk to the various health services; others would take public transport or drive their own car. Others were picked up for their regular appointments at places like The Parks and the Southern Clinic. We were told that Nunkuwarrin Yunti also transports its clients to appointments at no cost, which was appreciated by participants:

*Easy for me to get to, good medical service and if I'm not able to get transported there by a carer or anyone in the family, they will come and pick me up (P#3).*

Another person had experienced problems with transport to services since he had stopped driving himself:

*Because see they ... they spread these things out now, you know. You've got to go to Plympton for eyes and you've got to go Cowandilla for medication and so that's a bit of a bind I find. So when I have to catch buses, it'll be awkward. Or I'll have to get someone to help me though (Elder Men's group).*

One person believed that many Aboriginal people do not use medical services because of transport problems, and felt that more home visits by health professionals were needed. Inconsistent access to cab vouchers was

also reported as a problem affecting access to health services. Lack of mobility aids also impacted on ability to access services. For example, one carer had experienced problems with wheelchair access to services. Others spoke of the high cost of walking frames. A participant who cared for a relative with multiple chronic diseases revealed that several attempts to get a wheelchair had failed:

*I still don't get nothing. No. We thought we would have to get him a wheelchair at one stage because he was...he could hardly walk. We had to buy, I mean literally, we could not hire, we could not rent one, we could not have one given to us. We had to buy one. There was no way I could afford to buy him a wheelchair (P#11).*

Participants knew about several community services that help people with alcohol and other drug use problems and mental health problems. Due to their central location, the Aboriginal Drug and Alcohol Council and Nunkuwarrin Yunti are available and have organised initiatives in the metropolitan area that can cater for those things, participants said.

The participant from the Aboriginal Prisoner Support Service said that clients used the health services at Nunkuwarrin Yunti and Adelaide Community Health Service. These services were mainly used for the clients' methadone treatment, as most were heavy drug users. Group discussions were held at the Aboriginal Prisoner Support Service to address problems or drug-related issues. If needed, the service arranged extra counselling. It also provided transport to services if the clients were short of money.

Participants discussed provision of information by health professionals. Members of the women's group indicated that doctors sometimes give out good information but sometimes you have to push them for it. One woman was very satisfied with the information provided by her doctor:

*He gives me more information than any other doctor can. Actually there are two of the doctors down there and they both explain everything (P#5).*

Another received a clear explanation of what was wrong with her and had also received her medical report in writing. One woman appreciated how the doctor had shown her x-rays of her brain and explained her condition through this illustration. One person said that it was his own fault if he did not receive enough information, and said 'I should ask anyway' (Elder Men's group).

However, not everyone was happy with the amount of information provided, particularly in regard to medication. For example, one participant told of an incident at a mental health clinic in Port Adelaide where, after waiting a considerable time to see the doctor, she was provided with medication, a repeat prescription and a new appointment, but no information about the medication (P#10). Fortunately members of her family were health professionals and could explain the medication to her.

Another participant identified a need for better information specifically in regard to asthma, saying: 'Not too many Nungas realise how dangerous asthma can be' (P#3). She acknowledged that doctors do talk to clients about effective use of inhalers, but said:

*I don't think it (information) goes down...they need to be educated more...they trust doctors, but they don't believe them (P#3).*

One participant had received medicines without instructions on the packet and had to ask pharmacists for information sheets. This person was particularly worried about providing adequate information to older people, or to people who do not like to ask. A carer talked about having insufficient information from health professionals when the person she was caring for was profoundly medicated during an anxiety attack. Hence she questioned the treatment, as she had been unable to understand what had happened.

A participant had experienced discrepancy of information between the local doctor and the Queen Elizabeth Hospital regarding her diabetes medication. She felt that there was a lack of communication between the hospital and GP:

*I mean, you know, you get lost if you listen to one and then one tries to tell you something else or overrides that (Women's group).*

Some people were confused by changes in medication following a brief visit to hospital. Another woman had, however, experienced a good level of communication, as her contact doctor at Queen Elizabeth Hospital would write to her local doctor about any changes to medication.

Carer participants related a number of sad experiences and it became apparent that some had great need of better health and other services. For example, one older participant, in poor health herself and dependent on help from family members, was caring for her young relative with severe physical disabilities and psychological problems. We were told how all her attempts at obtaining assistance for herself and her relative had failed, and how the situation was desperate. Assessment, home help, modifications to the home, respite for both parties, counselling and peer support for both, and attention to their special needs were all urgently required. The researchers advocated for this family (see below). Other carer participants felt isolated and unsupported. They were interested to hear of support groups aimed at carers in general and those for specific conditions (e.g. the Kidney Foundation).

Emotional instability and mood swings were also mentioned as situations that could cause much pain to carers. Carers emphasised the serious need for respite in such situations, but had great difficulty finding it. Participants mentioned that they occasionally found Aboriginal people to provide the respite. It was important that the respite carer was of Aboriginal descent but participants acknowledged the difficulty in recruiting such persons, as many

Aboriginal people have a police record and hence are not allowed to work in such services. Carers often had to rely on other family members to get a break.

## General health issues

As the participants were mostly older Aboriginal people, general health issues were quite significant. Their health problems included arthritis, prostate problems, heart and artery problems, kidney problems, back and knee problems, polio, liver disease and high blood pressure. The majority of participants suffered from diabetes and some had serious eye and/or foot problems as a result.

Carers said they came to understand health problems 'by trial and error'. If the person they cared for experienced problems, they had to find out first hand and deal with them on the spot:

*There's no sort of training to tell you - your person's had a stroke - how to deal with that because you're in it up to your ears. And you have to deal with it the best way you can (Elder Women's group).*

Participants acknowledged the importance of taking care of the body and most seemed to have an understanding of their own health. All of the carers had considerable health problems themselves, but all prioritised the health of the people they cared for above their own.

## Medicines

The interviews mostly covered information about medicines used by carers. The majority did not know the names of their medications, but knew about what they were for and recognised them by appearance. One 'just knew in her mind' (P#2). Some medications were mentioned by brand name (e.g. Bactrim, Aropax) or more generally described (e.g. fluid tablets, diabetes medication).

One person reported that she had used Diazepam and other medicines for panic attacks and depression, and had received injections of Diazepam when her condition was very bad. This participant had attempted to overdose twice, but her condition had now improved so she was able to manage her medication together with her carer. Both had learnt about the illness and medication by 'living with it'. They were helping each other, as the woman had informed her carer about the condition and medication, and what precautions to take if a panic attack occurred.

The majority disliked taking medication but acknowledged that it was necessary for their health. A member of the women's group always questioned if the doctor prescribed her new medicines and asked for

information. Participants said that some medication could affect the 'maleness' in Aboriginal men, and that could bring problems into relationships and families. One carer said the following about her relative's attitudes to medicines:

*He hates it. Hates...he's got a drawer where all his tables are and he hates it. He just...just hates his drawer. Calls it his hate drawer (P#11).* Despite hating the medicines, this person took his medication 'religiously'.

Some worried about the interaction between medicines, especially if taking many different medications. Because of the multiple illnesses some participants suffered, side effects of medication became apparent. One found he got sicker from the side effects of his arthritis medication, so he had stopped taking it and was managing reasonably well. Another participant found it difficult to cope with the many changes in her illnesses plus the different medications.

*They're never gonna heal because for one thing medication affects one lot of illness...another lot of medication affects the body itself and you've got another lot of medication which may be fighting against another lot of medication...and so while that's happening in my body, it's not getting healed or it may settle for a while but that's about it (P#3).*

The men's group also mentioned the risk of overuse and how some people go from doctor to doctor for medication.

According to the participant who worked for the Prisoner Support Service, clients rarely refused to stay on the methadone treatment, as it 'gives them another high apart from the real stuff' (P#8). He was unaware of what other medication they might be on. He had experienced clients being unable to stick to their methadone program, going walkabout and not benefiting from the help they received at the Aboriginal Prisoner Support Service. However, most clients using this service tended to have a broad range of knowledge about methadone.

Fortunately, one carer had good knowledge about medication. She had experienced her husband being prescribed medicines for epilepsy without even suffering from this disease. Due to her knowledge she had prevented him from taking this medication.

There seemed to be some confusion about effectiveness of different brands of the same drug. Some participants had chosen to pay extra for the original brand even though they could have got a cheaper generic type of the identical drug.

A majority of the participants used dosettes for their medication and found them easy to use and understand. The chemist or health workers filled the

dosettes with medication. Some participants filled the dosette themselves and some had assistance from carers or family members in reminding them to take their medication. One participant used a system where she would tick off whether she had taken her medication.

It was agreed that it could be hard to remember to take medication, especially when unwell. One participant said:

*I know which ones to take but I do get forgetful. And I forgot, I've done that with my morphine. I'm on morphine as well. Now, there's been times I've forgotten whether I've taken morphine or not so what I've done is, I've had to leave it off all day until the night dose, because I think if I can't remember, an' I don't know if I've taken it or not, what damage could I be doing to myself if I take two lots? (P#3)*

This person was considering the use of a record book to avoid such confusion. On another occasion the same participant's doctor had prescribed too much morphine. The participant realised the potential for death had the mistake not been detected, and complained to the doctor about the mistake (P#3).

Clients on methadone residing in a house run by the Aboriginal Prisoner Support Service were monitored by the health service to ensure that treatment was followed as prescribed.

Another participant, despite having complex health problems requiring multiple medications, did not receive any assistance in managing medication and was satisfied that it was working as intended.

The cost of medication was a problem for most participants, one of whom relied on a relative who had to work to pay for medicines. A carer relied on government benefits to pay for medication, and revealed her frustration at not being able to find work herself because she would lose this assistance, saying: 'the government doesn't give you any incentives to do anything' (P#11).

Participants on pensions found it difficult to afford medication sometimes. Some would go without other daily necessities in order to afford it. Others had been without medication many times when short of money. Some participants were fortunate to have a good relationship with certain pharmacies where the pharmacist encouraged regular clients to get their medication when they ran out and pay him on pension day. One participant who was new to Adelaide talked about waiting until pension day for her medication. Other participants encouraged her to go to those pharmacies known to be sympathetic.

Running out of medication happened occasionally. As a result one participant had felt dizzy and his son had helped him to get his tablets. One



woman had assistance from a close friend and carer who ensured that she had enough medication. Another said there was always someone you could get the medication from if you ran out.

Some participants were aware that sharing medication happened in the community but only one shared with his mother sometimes. This person only shared if he knew the medication had the right strength - he, as well as other participants, was aware that sharing was wrong. One elderly male had this opinion on sharing:

*No, definitely not. Er, I'm pretty strict with that type of thing, you know. What it does to me, they help me out, but it may not help another person. Perhaps that could cause irreparable damage. They might be subject to that medication. Oh, I am very strict about that, yeah (P#9).*

Participants emphasised safe storing of their medications, and used various hiding places and storage facilities to keep medication in drawers or locked away out of reach of children. One also mentioned keeping medication sealed to avoid contamination. A person on morphine did not lock it away but carried it with her at all times. One participant brought up the need to store medicines safely in the home, as there could be drug-dependent visitors.

If participants had any out of date medication or medication they did not use anymore they would take it back to the doctor, the chemist or flush it down the toilet. Only one person did not know what to do with old medication. One mentioned she would rather go without than take out of date medication.

These participants did not use traditional medicines. One did not want to use them and some said they did not know enough about them. In regard to mental health, one member of the men's group knew of someone who had had a nervous breakdown and had been helped by a traditional healing practitioner who:

*...slept there for two weeks, got him out of his mental health position and got him back to work - two weeks (Men's group).*

Participants found it frustrating that traditional healers are not usually recognised by white health professionals. Participants of the men's group spoke about the value of thousands of years of knowledge and how it should be applied, but that the health system is not willing to pay for it. The women's group talked about how they felt non-Aboriginal people do not listen to the considerations Aboriginal people have about a person's health or treatment, and that they do not acknowledge the use of traditional healing practices.

## **Mental health (social and emotional well being)**

Not everyone was certain about a definition of mental health/social emotional wellbeing, but most participants gave an example. They mentioned dementia, stroke, head injuries, alcohol-related brain damage, depression, drug and alcohol use, memory loss and Alzheimer's disease.

One participant felt that the medication she was on for her physical problems affected her feelings and emotions. The participants had themselves experienced, or cared for, or knew others with a range of mental health problems including psychological distress, autism, attention deficit hyperactivity syndrome, bipolar disorder, schizophrenia, brain damage, depression and stress. One spoke about stress as 'something everyone had tried'. Participants mentioned that delusions and difficulty in making decisions were part of mental illness.

The participant from the Aboriginal Prisoner Support Service informed the research team that some of its clients had drug-induced mental health problems. He emphasised that the Aboriginal Prisoner Support Service was not a health service, but a place aimed at teaching clients about cleanliness, hygiene and to preparation for life in society, thus providing assistance from a harm minimisation perspective. Clients with severe mental health issues were not suitable for the house. The prisoner service had experienced one client with mental illnesses, and the service had not been able to cater for him and his needs.

One participant had many unfortunate experiences with mental health issues. We were told that her relative with schizophrenia was jailed, that his request to see a psychiatrist while in prison was denied, and that he took his life in jail. Of course this dreadful situation has caused great anger and distress because, as she said: 'These things are not supposed to happen in jail. Kids are supposed to be safe in jail' (P#11). To make matters worse, she found there was a waiting list of several months before she could obtain support and counselling from the mental health service. Instead, she found help in a group of Aboriginal Elders who meet regularly for mutual support, as everyone in the group had been affected by tragedy.

In a focus group interview, the Aboriginal researcher identified that there is not enough information around for Aboriginal people to recognise mental health problems. In response to this, a male focus group member suggested that Aboriginal people now have almost every ailment 'in the book', including mental illness, due to multiple factors:

*People don't care anymore about their health because no one listens to them. They don't address it, they don't pass on the knowledge. It is a rife in the community. I've still had to deal with some of this nonsense and*

*you see that when the power goes from a group of people that are fully in control...the whole world crumbles and this is a sadness to watch... When you start going to the doctor and giving the doctor the power over your life and the power to the white people then you lose all your knowledge base and you become nothingness (Men's group).*

Another man talked about a particular case that had upset him where an Aboriginal girl had been wrongly placed with a foster family, with repercussions on her mental health:

*And they (foster family) were all nutty and she thought that was the norm. And so she acted nutty and yet all the psychiatrists looked at her and thought she was nutty. When I looked at her, a bloke said to me, what do you think? I said I think she's perfectly normal. And anyway they put her in a health care. She went to Flinders Medical Centre, had shock treatment and medication. She went the whole run and I thought this was stupid (Men's group).*

The women's group identified that mental health issues among Aboriginal people had to do with cultural disempowerment:

*Well I think that it stems from cultural genocide. And I think people who have their culture ripped out from underneath them, people who have been dispossessed. People who have been taken away from their communities without their consent. It all contributes to the ... the health of Aboriginal people (women's group).*

They considered that non-Indigenous medical treatments aimed at the brain would not have much effect as the pain is in the heart. Another participant believed that most people who have mental health problems in Aboriginal communities have to make cultural adjustments continually. The stolen generation was also mentioned in that regard. It was therefore easier to turn to alcohol and drugs and other substances to mask the traumatic experiences of having to cope with the changes - this is a major factor relating to the cause of all sorts of mental problems according to participants. However, another participant emphasised that joking about her mental illness seemed to relieve the tension sometimes. She continued:

*I'm not ashamed about it because when you look at it, everybody does suffer from depression at one stage in their life (P#10).*

Physical illnesses in Aboriginal communities were also found to affect people's social and emotional wellbeing, and losing a loved one was identified as the biggest worry. Members of the women's group gave the example of an Aboriginal male losing his inhibitions after a stroke, how that would damage the family structure and how caring for that person would be very challenging.

Participants said that Aboriginal people with certain conditions are sometimes misinterpreted as being drunk. Therefore, there was a need to provide people with information bracelets that would indicate their illness. However, it was identified that one community member had been waiting for over twelve months for such an identification band.

A participant caring for a physically and mentally ill relative also identified that there was lack of appropriate help available. Despite multiple problems, her relative was apparently 'not disabled enough' to be eligible for outside help. This left her with a 24-hour burden of care, causing her significant worry and depression. This participant coped with the situation through support from family and by mixing with Aboriginal peers:

*It's daily and it's 24 hours of, like you are on call 24 hours of a day and it wears you out. It really wears you out ... And it's the company here that ...that keeps me sane (P#11).*

This woman gained great benefit from her peer group in coping with the issues in her life, and in her role as a carer. Therefore, she suggested some sort of carer society where there would be assistance in dealing with these issues, not the least of which would be to receive respite. All participants agreed on that. As an extreme but true example of the lack of appropriate services available, this woman revealed that in order to get the respite she desperately needed, it had come to the point once where she had lied to the doctor to prove her 'insanity'. She said:

*I kept telling the doctors I was going to poison his potatoes. Oh no. I was just. I was really down...I just needed a break. That was the biggest joke. I took all my beading...I needed to disappear...All I wanted was a nice, peaceful, even a week's break (P#11).*

This woman ended up in a mental health hospital for a short time and found this 'trick' very helpful in getting some rest. This account indicates the severe lack of services and the extreme measures that people must take in order to access the respite they need.

Participants were worried about the way mental health problems were managed for Aboriginal people. They had experienced situations where psychiatrists and psychologists made statements about Indigenous people without consulting the families or communities, and some people had been detained without consulting family. They emphasised the importance of the family in managing such problems.

All agreed that it is very challenging for a family to care for someone with mental health problems. Therefore it was suggested that families should have networks where they could support each other to deal with such issues - to have other people to talk to and to build up your strength to cope with

it, including building up the family's strength (e.g. a carer society). One person suggested that perhaps such networks or groups could be organised via the chemist. Extended family was also mentioned as essential in this regard. It is 'expected' and is part of the culture's obligations. One participant mentioned the fact that even though it is anticipated that you will care for your elderly family members, some young Aboriginal people do not see it as their responsibility. She found that a big concern for Aboriginal Elders was that some services that were needed were not available.

Participants were worried about the prevalence of depression and suicide among young people, which is of great concern and stress to the community. Inadequate support for their family members was highlighted. For example, one participant was unable to access timely legal assistance, crisis intervention or counselling when a relative died in custody. Participants agreed on the urgent need to address these problems, and suggested that organisations with funding should draw the community together to be able to talk this through and establish services where counselling as well as legal/financial aid could be provided. Participants also suggested that when young Aboriginal people go to jail, organisations could initiate visits from people/family outside. The participant representing the prisoner services reported that they provide assistance to pre- and post-prisoners, and that this is found to be beneficial to clients and their families, due to their focus on harm minimisation and teaching people 'how to live again' (P#9). However, this service was only able to cater for four clients at the time, often leaving female clients without the possibility of benefiting from the service. Therefore, another house was needed to cater for both females and males.

Participants emphasised that people with mental health problems may be at risk of unsafe medication use. One participant said that people with depression, Alzheimer's disease or dementia may not remember if they have taken medication or might not store it safely, and managing medication may be too much responsibility. Use of a dosette and visits from the RDNS to assure that the medication is taken correctly were mentioned as helpful in such situations.

Another participant said that some people may become dependent on medication, that medications can affect moods, and that some would be 'a nerve wreck' if they did not get their medication. She wondered if lack of medication sometimes made Elders 'snap at you'. She thought some older people did not always realise that their mental health had declined, and could make mistakes with their medications. Resentment and hurt feelings could result when family members tried to step in.

In managing medication for a mental health problem, one participant emphasised that she was lucky to have good friends and assistance from

Aboriginal health workers and the City Homeless Aboriginal Support Team. She also acknowledged the support of the Aboriginal Elders group at Kura Yerlo. She had not received the necessary care and support from mainstream mental health services. Nunkuwarrin Yunti Aboriginal Health Service had also failed to help her, as visits from a psychiatric nurse that they arranged had never eventuated (P#10). Understandably, these experiences have led to a lack of trust in the system.

Another participant who cared for someone with a mental health problem reported not being able to access any assistance from the mental health services. Frustrated, she said:

*Mental health, I'd like to know what it defines. Defines mental health. Like to know where you access so much of all these things that are advertised for mental health carers. I'd like to find out when you do access them, how come they can't help you or you have to buy this equipment that is so expensive that you can't afford it anyway. And who actually does apply for it? Or qualify for it? (P#11)*

## **Alcohol and other drugs**

Participants identified that there are many problems with alcohol and drugs in their community and, unfortunately, many in their close families. Only a few participants drank alcohol themselves and they did not use illicit drugs. However, most knew of, or were related to someone with such problems, which included dealing drugs as well as problem use of alcohol or drugs. They knew of people who would drink from morning to evening and it would involve a lot of arguments, screaming and abuse. Some participants believed that people start using alcohol and drugs experimentally and because of peer pressure. The group of older men said alcohol was not a problem when they were young. It never worried them and had become a widespread problem only in the last 20-30 years. Alcohol consumption, heroin and amphetamine use, and petrol sniffing began as an escape from boredom, lifestyle, illiteracy or depression. The majority mentioned that problem use of alcohol and drugs among Aboriginal people was associated with loss of culture and stolen generation issues.

Doctor shopping was reported as common among people seeking drugs like Valium, Rohypnol and Serepax, and it was revealed that it was easy to get these kinds of medicines as 'they know where to go' (P#11). It was reported that sometimes these drugs are obtained from relatives with chronic disease or even cancer. Many participants mentioned the problem use of alcohol and drugs in relation to mental health disorders, as participants knew of people who would mix their prescribed medications with alcohol and other drugs.

Clients residing at the Aboriginal Prisoner Support Service were on bail or parole. They were therefore on strict orders not to leave the house. They

wore ankle bracelets as monitors, so their access to alcohol and other drugs was very limited.

## **Discussion and recommendations**

This project explored issues, contexts and needs impacting on safe medication management by Aboriginal people with physical and mental health problems and their carers in the Metropolitan Adelaide area. The findings fall into the following broad themes, all of which affect use and management of medication, directly or indirectly:

1. Education.
2. Need for accessible, affordable and culturally appropriate services.
3. Information and support for safe medication use.
4. Carer support and respite.
5. Improved health services.

It is notable that the findings confirm those of the pilot study in Northern Metropolitan Adelaide [1] (Attachment 8) and our research in other parts of SA conducted as part of the statewide project (Attachment 1-7).

### **Education**

Participants identified that some professionals in the community need more knowledge and training in mental health and Aboriginal social and emotional wellbeing. People have been wrongfully treated because of lack of understanding and knowledge.

Recommendations:

1. Provide mandatory accredited training for all health and human service workers, and carers, on Aboriginal mental health and medication management. This should include cultural awareness and culturally appropriate practices.
2. People with diseases that can be wrongly recognised as alcohol/drug-related behaviour need to be easily identified by wearing a wristband or similar. Access to this equipment needs to be facilitated.
3. Provide better training for police and other professionals (including the judiciary) in recognising mental health problems, because the behaviour of Aboriginal people is often stereotyped or misinterpreted, especially among people who are drinking alcohol.

### **Need for accessible, affordable and culturally appropriate mental health services**

Participants identified problems with social and emotional wellbeing in their community. Cultural disempowerment, extensive physical illness, deaths in families, depression and youth suicides are all factors that have affected the

community. It became very clear that there is a need for improved and appropriate services that can address the severe problems that Aboriginal community members meet on a daily basis. This is especially so for clients and carers.

**Recommendations:**

4. More Aboriginal people should work in health and community services e.g. centres for mentally ill. Non-Indigenous people should not make policy decisions on behalf of Aboriginal people without consulting and negotiating with them.
5. The important role of the family must be acknowledged when important decisions are made for Aboriginal people regarding mental health issues. If people are detained, families must be involved. If they go before the guardianship board, the Office of the Public Advocate or the Public Trustees, all of those people must have Aboriginal people employed by them. They must not make any statements or decisions that affect that Aboriginal person unless they talk to the families.
6. Networks to help the community need to be developed - people need to cooperate with organisations and service providers in order to cope with social and emotional wellbeing issues. Better links between the various services are urgently needed.
7. The specific Aboriginal mental health services have proven to lack the assistance that is required by the community. Immediate attention is required to address this issue.

## **Information and support for safe medication use**

Participants identified various issues regarding medication management, including running out of medicine, lacking information and keeping medication safely.

**Recommendations:**

8. Devise a system for storing medicines so that visitors or other family members cannot take them to use or sell. Local pharmacies may be willing to look after some medications for clients.
9. The current relationship between some chemists and their regular clients, which allows necessary medication to be obtained on credit, should continue and be encouraged more widely.
10. All medication must have instruction sheets in the packet, including medicines that have been packed into dosettes or Webster packs.
11. Develop different approaches to instruction in asthma medication.
12. Raise awareness about the identical active ingredients in original and generic prescription medicines.



## Carer support/respite

Caring for a person with mental and/or physical problems is exhausting, stressful and expensive. Some participants were elderly carers of people that required extensive attention. The carers had health problems themselves in addition to having to deal with problems with the person they cared for.

Recommendations:

13. Arrange a culturally appropriate respite service for carers. According to participants there is no need for special qualification:  
*All you have to do is have an understanding of everything. You know like a feeling for people who you're going to work with (Women's group).*
14. Ensure that carers obtain assistance with their own health and other problems, such as home visits from Aboriginal health workers or the RDNS for check ups, assessment of social and emotional wellbeing, medication management (ensure medication is taken, right dosage, prevent running out) and help with accessing appropriate health services, counselling and accommodation services.
15. Establish an Aboriginal carers' society. 16. Lobby for funding specifically for respite care for Aboriginal people with mental health problems.

## Improved health and other services

Despite the evidence that some participants expressed satisfaction with health and other services, many areas of the health services were identified as needing improvement.

Recommendations:

17. Encourage health professionals to visit people in their homes and communities, because Aboriginal people do not have transport and cannot easily visit health services themselves.
18. Wheelchair access must be improved at health services. Costs of aids and transportation must be considered, as this will prevent people from using them or be at the carer's expense.
19. Better access to a pool and gym, preferably if some Aboriginal women could go together.
20. Provide counselling services for the elderly as they have many worries looking at their future and coping with issues in the communities such as young people's drug use, and their physical and mental health.
21. Improved services at Centrelink, social welfare services, and banks, and preferably employ more Aboriginal people in such services. Improved assistance in dealing with financial, legal and correctional issues is also needed, as well as an Aboriginal pre- and post-prisoner service for women.

22. Traditional medicines and healers should be made more easily available, their skills and knowledge should be recognised by the mainstream services, and they should be paid accordingly.

## **Early outcomes and future plans**

There were a number of incidents and situations affecting individual participants that were uncovered during the data collection. Our research approach has always been to put participants' needs above those of the project, and therefore researchers addressed these matters where possible, or referred to relevant services. For example, one of the interviews revealed a tragic situation in which both an elderly carer and her young disabled relative were in urgent need of support and practical help. A letter of advocacy was written by the chief investigator and sent to relevant decision-makers for this family. Similarly, the interviewer assisted another participant to understand and respond to an official letter. Another person was provided with information about the Kidney Foundation to help her care for her relative with renal failure. One participant lived in accommodation that was unsuitable for a wheelchair, and the researcher helped with an application for a transfer to another house. Thus, the interviewers implemented immediate changes to problems participants identified about provision of, and access to health services.

The pilot study for this larger project was conducted in Northern Metropolitan Adelaide, and the report and its recommendations have been useful in lobbying for changes to policy and practice in the metropolitan area. These early outcomes are described in detail elsewhere in this report (see Chapter 8). They include draft memoranda of understanding between Muna Paiendi and Lyell McEwin Hospital, and between Northern Metropolitan Community Health Service and Elizabeth Community Corrections. Both memoranda are aimed at coordinating care and support services, and ensuring culturally appropriate follow-up. Other initiatives arising from the pilot study include the provision of financial counselling from Aboriginal Legal Services at Muna Paiendi, specific health care training for Aboriginal community members and workers, and use of Aboriginal Primary Health Care Assistance Programme funds to provide holistic care for Aboriginal people.

## **References**

1. de Crespigny, C., *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers - A Pilot Study in Northern Metropolitan Adelaide*. 2002, Bedford Park, South Australia: Inprint Design.

# Attachment 7

## Report on research conducted in the Maitland region

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**This report was prepared by:**

- Helen Murray
- Charlotte de Crespigny

Engagement of the Aboriginal community in Maitland was not originally planned at the outset, however in response to the direct request from Narungga Elder Care Service in Maitland for us to visit them, once they had heard of the project we engaged in preliminary discussions on mental health and safe medication issues. Subsequent visits are planned, again as requested by the local Aboriginal community. This pragmatic approach is in keeping with the participatory action research framework of this research program, and demonstrates the team's commitment to addressing issues as they arise and being guided by the wishes and priorities of particular Aboriginal communities.

Unlike other regions in which this large SA-wide project was conducted, the research team did not initiate contact with a local Aboriginal health service in Maitland. Instead, the CEO and Director of Nursing of the Maitland hospital, who had heard and wanted to know more about the research program, approached the team. Members of the team then had a discussion about the research program with the CEO, some of her staff and a group of local Aboriginal Elders, who then invited the team to return.

In common with findings from elsewhere in SA, the Maitland group of Aboriginal Elders agreed that living with mental health problems was a part of most Aboriginal people's lives. They had also experienced many occasions when mental illness, complex health problems, alcohol and drug problems, and medication issues caused ongoing and extensive difficulties for carers and other family members.

They described and observed that Narungga Elder Care Service follows a protocol for safe medication management. According to the protocol, a single member of staff takes all clients' prescriptions to the pharmacy on one day and returns them centrally to Narungga Elder Care Service in Webster Packages the next day. It was noted that some of the Webster packs were labelled with symbols for time of day for those whose literacy or eyesight was poor. The packaged medications were then delivered to clients by a

registered nurse and the Aboriginal health worker or paid Aboriginal carer employed by Narungga. Delivery was reported as being done early in the day because people were more likely to be at home, and so the packs could be delivered to the correct person or their carer. This also provided an opportunity to discuss clients' medications and combine medication delivery with routine regular maintenance health checks such as blood sugar level and blood pressure.

The research team was told about a locally funded carers' organisation that included some Aboriginal carers. This organisation was described as being able to attend to local needs in the local area, and was considered more effective for the community than the national carers' association, despite the latter's links with a range of government departments and funding bodies.

There were appreciative reports by some Aboriginal women who discussed their good rapport with some local medical practitioners who spent time explaining investigations, illness processes and treatments. There were also many appreciative comments from Aboriginal Elders about their health practitioners' holistic approach to their care, whether at the central location in Maitland or during home visits to clients at the local Aboriginal settlement at Point Pearce. Besides the GP there were only two people involved in mental health care in the region - a nurse based in the Division of General Practice and a social worker - and there was no mention of a drug and alcohol specialist in the area.

A number of Aboriginal people are residents in the local aged care facility in Maitland. It was reported that although it was resisted at first, the aged care facility is now accepted by former carers/family members as a good solution for Aboriginal people with dementia and their loved ones. It was reported that the community's attitude to long-term residential care of dementia sufferers occurred as a result of improvements in the consultation process between the regional health authority personnel and the Aboriginal community, as well as having better-informed staff at the facility.

We were told that there are sometimes problems for families when older Aboriginal people who move back to the area to be with siblings and other family members may not be able to take on an additional caring role, especially when the family is already coping with multiple problems. Concern was also expressed that some younger Aboriginal people might make inappropriate recommendations about the care of their older relatives.

The Elders indicated that there were problems with alcohol and other drugs in the Maitland community. However, they requested a subsequent visit to discuss this sensitive subject. The research team has planned a visit in July 2003 and has committed to assisting, as needed, beyond the life of this current project.

As in other areas of SA, we were told that detainment of Aboriginal people under the Mental Health Act has caused some serious problems, as detained people are sent to Adelaide, sometimes in inappropriate surroundings. They may be released in the city without families, carers or local health practitioners being notified or consulted, or having the opportunity to contact, support or be with them.

To date the research team has had little opportunity to interact with local health workers other than the CEO and some staff from the hospital, and staff of Narungga Elder Care Service. However, they expressed interest in professional education about mental health, medication management and substance use. Such education needs to be delivered locally, rather than sending people away for training, as this puts undue pressure both on local services with few staff and resources, and staff with many community, work and family obligations.

# Attachment 8

## Pilot study in Northern Metropolitan Adelaide

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### **Contributors**

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### **Acknowledgments**

The project team acknowledges the generosity of the Aboriginal clients, carers and health workers who shared their stories and insights. These participants cannot be named for confidentiality reasons, but their individual contributions are very much appreciated. We also thank the Steering committee members for their guidance and advice. Finally, the financial support of Rotary Australia and the Commonwealth Department of Health and Aged Care is gratefully acknowledged.

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## Introduction

Poor health, premature death and grief continue to severely impact on the cultural, physical, psychological and family well being of Aboriginal communities. Accidents, infections, renal disease, diabetes, hearing and sight loss, heart disease, poor nutrition, smoking and excessive alcohol consumption, dementia, acquired brain injury and other mental health problems can all be directly linked to chronic poverty, social dislocation, grief, lack of culturally appropriate services and the long term cultural disruption of Aboriginal Australians, wherever they live[1-8]. Therefore, many Aboriginal people with mental disorders such as dementia and Korsakoff's Psychosis also have coexisting health and social problems, and require ongoing, intensive support from their carers and other family members. The ongoing burden of caring for someone living with such complex health problems places inordinate strain on the physical and mental health of Aboriginal carers and diminishes the overall well being and capacity of these individuals and the Aboriginal community as a whole.

The literature highlights social and economic issues associated with the use of medications, such as intoxication, excessive use and dependence, adverse drug reactions, hospital admissions, accidents and falls, misdiagnosis or exacerbation of dementia, and psychological effects of polypharmacy[9-11] . A search of the literature did not reveal any research on medication use specific to Aboriginal cultures other than that reported by one of the investigators on this project[9]. Medication management for Aboriginal persons and their carers is problematic because of cultural issues, limited access to quality culturally appropriate medication information and support, as well as differences in knowledge, personal resources and skills[9]. Previous research has indicated that older urban Aboriginal women, like their non-Aboriginal peers, recognise medications by shape and colour, and rely heavily on memory for dosage and time of administration, often involving more than one medication[9]. There was evidence that medications were shared amongst family and friends or reduced in dosage, and that personal medication management for diabetes, and prescribed diet and exercise, were poorly understood and/or managed[9]. Further to these findings, the cultural beliefs of older urban Aboriginal women may be that 'white man's medicines' are not always valued or complied with from their cultural perspective[9]. Aboriginal home care workers in contact with Aboriginal clients and their families have also highlighted the lack of culturally appropriate medication education and support for their clients and themselves[9].

There have been few comprehensive national studies into the nature, context and impact of excessive alcohol or other drug use on the morbidity and mortality of Aboriginal Australians[1], apart from investigations based on national statistics [4, 7, 8] .

The Aboriginal community in South Australia is gravely concerned about the impact of excessive drinking and other drug use on their people, even though this behaviour occurs in a smaller percentage of Aboriginal people than non-Aboriginal people[1, 12-14]. Excessive licit and illicit drug and alcohol use are bound within a range of complex life issues, being intertwined with medical, psycho-social, mental, generational, spiritual and cultural conditions experienced by Aboriginal people. These conditions can in turn reflect and compound the already markedly poor health status of many Aboriginal Australians.

The combination of prescribed medications together with other substance use, eg over the counter medicines, illicit drugs or alcohol, can compound the physiological, psychological and social problems of mentally ill persons[12]. Medication use in persons with dementia requires special consideration because of declining cognitive ability, memory impairment, co-morbidity and loss of physical function. Furthermore persons with dementia illness may not be able to express verbally their pain or other symptoms and may not be able to communicate their need for appropriate treatment[15]. Quality use of medications by mentally ill persons, and their need for palliative care has been recognised but this requires extension into culturally specific groups such as Aboriginal persons.

## **Aims and objectives**

The aim of this study was to explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications. The project was supported by a grant from the Australian Rotary Health Research Fund. Funding constraints limited the scope of this project to interviews with consumers and a focus group discussion with health professionals in the Northern metropolitan area of Adelaide. This project was a pilot for a larger project currently in progress to investigate these issues SA-wide and funded by the Quality Use of Medicines Evaluation Program through the Commonwealth Department of Health and Aged Care. Taken together the findings of both projects will inform statewide recommendations and strategies for improved, culturally appropriate policies and practices for medication management by mentally ill Aboriginal Australians and their carers.



## **Participants and methods**

### **Research Approach**

A collaborative approach was taken involving a partnership between the investigators from the School of Nursing and Midwifery at Flinders University and the Aboriginal Drug and Alcohol Council (SA) Inc. The research was planned and conducted in consultation with representatives of the Aboriginal people living in the Northern metropolitan area of Adelaide, to ensure that the research was responsive to the needs of the Aboriginal community and conducted in a culturally acceptable manner. A qualitative research design was chosen, in which rich experiential data was collected through in-depth interviews and focus groups with consumers and service providers, followed by thematic interpretation. The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of SA. The research conformed to the NHMRC guidelines for ethical Indigenous research[16].

### **Steering Committee**

A steering committee comprising the research team, representatives of Aboriginal groups and those who provide health and social services to them was convened to guide all aspects of the research (Appendix 1). Quarterly meetings of the steering committee were scheduled. The steering committee advised on recruitment of an Aboriginal research assistant acceptable to local Aboriginal communities, engaging potential participants, drafting and piloting the interview guide, followup on issues raised by participants, and draft reports and recommendations. We have used a similar approach successfully for previous research on medication use by older Aboriginal women[9], consumer-driven projects[10, 17-19] and other research[20, 21].

### **Selection of Participants**

#### ***Clients and carers***

Potential interview participants were adult Aboriginal people diagnosed with a mental health disorder, their carers or other adult family members, living in the Northern metropolitan area of Adelaide. Potential participants were identified by the Northern Metropolitan Community Aboriginal Health Team. The Aboriginal research assistant contacted them, and invited them to be interviewed for the project. It generally took several meetings to build a sufficiently trusting

relationship, which was facilitated by the Aboriginal research assistant's ongoing professional health worker and advocacy roles in the community.

### ***Health professionals***

In addition, a group of health professionals and other service providers from the Northern Metropolitan Community Aboriginal Health Team was brought together for a focus group discussion. The inclusion criteria for this group were that they provide professional health services or social support to Aboriginal people diagnosed with a mental health disorder, their carers or other family members. The focus group discussion was delayed for a considerable time due to a number of deaths and crises in the community.

## **Data Collection**

### ***Clients and carers***

Interviews were conducted by an Aboriginal research assistant, loosely following an interview guide. Participants could be accompanied by a friend or relative if they wished. Interviews were recorded on audiotape with written and/or verbal informed consent of participants. Participants were assured of confidentiality and anonymity, and could choose not to answer any question and withdraw consent at any time. The interviewer made notes (written and/or taped) to supplement the taped interviews. Eight interviews with clients and carers were completed. Another interview was conducted, but consent was withdrawn and tape destroyed.

### ***Health professionals***

The focus group was facilitated by members of the research team who made notes to supplement the tape recording. Ten health workers participated in all or part of the focus group. The same interview guide was used to steer the conversation. One Aboriginal health worker was interviewed on a separate occasion.

## **Transcription**

Tapes were transcribed verbatim. Sometimes the taped conversations were hard to understand and transcribers indicated missing words or phrases with question marks. A researcher listened to all the tapes and filled in some gaps in the transcripts, and made some corrections. The Aboriginal research assistant who conducted the interviews checked that transcripts were accurate.

## Analysis

Preliminary qualitative analysis of each transcript was conducted, based on the four major headings in the interview guide, ie demographics, health services, current health, medications. Key information and quotes were put under those headings while reading and rereading the transcripts and listening to the tapes. These were then categorised further, based on the issues and concepts mentioned in the grant application and interview guide and others that emerged from the interviews. A short summary was then prepared for each transcript. Finally, the findings from all interviews and the focus group were integrated into one document, to give an overall picture, highlighting common themes, key issues, similarities and differences. The process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and as deeper analysis occurred[22]. Other researchers from the team cross-validated the analysis[23].

## Development of Recommendations

The draft report was disseminated to the steering group and the Northern Metropolitan Community Aboriginal Health Team. Recommendations were developed in collaboration with these groups, based on the findings of the report.

## Findings

### Demographics

#### *Clients and carers*

Two interviews were with elderly Aboriginal women who care for family members with mental health disorders. Six interviews were with Aboriginal people who have a mental health disorder themselves (two women, four men, aged from early twenties to middle age). These participants were formally educated to primary or secondary school level. None were in paid employment or studying at the time of interview, although several of the younger men with a mental health disorder were thinking about looking for work soon, as their mental illness resolved. The women interviewed (carers and women with a mental health disorder) all had considerable family responsibilities. Interestingly none of the men interviewed spoke of their responsibilities to their families, although some acknowledged their families' support. All these client/carer participants received some sort of pension, sickness benefit or other government assistance.

All spoke English fluently, presumably as their first language. Their identification with particular Aboriginal communities or language

groups was not explored in these interviews. They all lived in the northern suburbs of Adelaide, generally in modest rental accommodation. Most lived with their families. The number of adults and children living in the home varied from 1-12. Several participants had been living at the same address for several years, but others had moved house frequently and a number travelled often (within Australia). Some were hospitalised repeatedly for extended periods as a result of mental health disorders.

No further information was obtained from interviews about the family and social contexts of the client/carer participants. However it may be surmised that most struggled financially with little prospect of improved socioeconomic standing in the foreseeable future. Many participants had close family ties which they relied upon for support, for example in caring for children, sharing of resources.

### ***Health professionals***

The health workers who participated were all members of the Northern Metropolitan Community Aboriginal Health Team, which is part of the Northern Metropolitan Community Health Service. They provided social and health support to Aboriginal clients in the community and clinic, including Aboriginal people with mental health problems and their families who lived in the Northern metropolitan area or who were transiently in the area. The Northern Metropolitan Community Aboriginal Health Team takes a holistic approach and deals with a range of issues including housing, finance, counselling, domestic violence, grief and loss, all of which impact on health.

Ten workers took part in the focus group, and of these all but one identified themselves as Aboriginal and were resident in the Northern suburbs of Adelaide. Four of these health worker participants also reported personal experience of caring for a family member with a mental health disorder.

## **Current Health**

### ***Mental health***

The client/carer participants named their mental health disorders as depression, schizophrenia, paranoid schizophrenia, manic depression, psychosis, anxiety and panic attacks, paranoia, bipolar disorder, psychotic episode, mental disorder, stress disorder, tension-related illness. They did not mention dementia. The mental illnesses varied in duration, from 2 months to 20 years. The onset of mental health disorders was mostly in early or middle adulthood.

Several participants who had suffered a psychotic episode spoke of their mental health disorder as transient, and were looking forward to a complete recovery. Others spoke of their mental health disorder as a long term health

problem of fluctuating severity, and believed that they had to live with their mental illness and take medication for life. A number of participants with a mental health disorder described their condition as stable or improving, but others were severely affected by mood swings, paranoia and sleep disturbances.

### ***Onset of mental health disorders***

Most participants first realised they had a mental health disorder after a psychotic episode, attempt at self-harm or other behaviours which led them to be admitted to a psychiatric unit. Generally they were first told by a non-Aboriginal health professional that the problem was a mental health disorder.

*The white folks told me, you know. (#9)*

*I was hearin' voices, I was seein' things...So I went to a white doctor, he diagnosed me as bi-polar, schizophrenic, suicidal, he slammed everything on me until – so he narrowed it all down that I've got bi-polar, mental disorderly and stress disorderly. (#5)*

Several participants linked their mental health disorder to heavy use of alcohol and other drugs.

*I think it was from the speed and the tablets and the whisky that I drank when I was ... young. (#2)*

Other client/carer participants felt that the mental health disorder was associated with traumatic life experiences such as abuse during childhood, grief, stress and tension.

*I believe that there's things there that have either happened to them, or things there that has happened within our family – in our extended family and our family, that is on their mind and they're not talking. (#1)*

*I went to [hospital] ... and they said it was severe grief, that's why I went there, I lost it, that's what they diagnosed, severe grief, that's why I'm on the Zoloft. It was in a way severe grief because before I went away I just locked myself away in the house...I had no one to talk to. (#2)*

*It's a tension illness, I think... Gotta learn to relax. (#9)*

The health worker participants echoed these views, suggesting that the cumulative effect of trying to cope stoically with prolonged stress, grief and loss often precipitates a mental health crisis.

Some health worker participants were concerned that mental health problems arising from traditional Aboriginal beliefs might be misdiagnosed.

*There have been people from traditional lands that have been brought*

*There have been people from traditional lands that have been brought down here and placed into [hospital], and been treated for some form of psychosis. We have to make the medical health teams understand that traditional people still follow the ways of the Law. And we must make the medical people aware of that because ... they can become physically sick or spiritually ill without it being anything in their minds ...and that sometimes they are wrongfully diagnosed as schizophrenics and that. (#11)*

One participant with a diagnosed mental illness believed initially that it was caused by a malevolent spiritual force:

*I thought I was caught because I was seeing [Aboriginal spirit]. I was hearing voices, I was seeing things, I thought I was caught. (#5)*

#### **Information about and understanding of mental illness**

Client/carer participants obtained information about mental illness from a variety of sources. Most were given basic information by general practitioners or on discharge from psychiatric units. The information was given as verbal explanations during consultations and in pamphlets. One carer said she only got information that she asked for and that she wanted more. Another participant was an avid reader and had obtained all the necessary information from books and pamphlets at various health services and community centres.

Some client/carer participants were sceptical and mistrustful of health professionals' diagnoses and physiological explanations of mental health disorders.

*I was trying to go cold turkey off dope and alcohol you know. I was going through withdrawals and I was having a few problems you know. Then I become suicidal and tried to [kill] myself and ever since then they've been pumping pills down my throat you know. And like I'm not suicidal you know like I don't want to take my life, I want to live man. I've got a lot to live for. (#7).  
They, they've given me pamphlets and that you know, about schizophrenia you know but I still don't understand it you know like, chemical, how can they tell if you got a chemical imbalance in your brain you know, how, how can they tell? (#7)*

The health worker participants also expressed reservations about medical explanations of their clients' mental health problems, and believed that some doctors may misdiagnose psychological problems as psychiatric illness. These health worker participants believed that their clients' mental health problems were often rooted in unresolved family stress, grief and loss, coupled with a tendency to not talk about problems due to perceived shame associated with not coping, and for

some people turning to alcohol or other drugs to blank out their pain. According to the participants such people eventually present in crisis at a hospital emergency department where they may be wrongly diagnosed as schizophrenic, depressed, psychotic, etc and be 'dosed up' with medication. There were suggestions that doctors might inadvertently put ideas or words into their patients' minds, (eg concerning self-harm, hearing voices) that confirm the suspected diagnosis. The following quote from the focus group illustrates this view:

*Everybody keeps stereotyping Nunga fellas, especially when the psychiatric assessment is being done in the hospital. You know, sometimes, it is just about depression, sometimes it is just about, like the Stolen Generation, all these issues, you know?.... No one is seeing it that way, you know, its just easy to fill out a medical file and saying they're schizophrenic or what. It's so quick, they're so quick to diagnose, like if you're quiet, or ashamed, which Aboriginal people are, but it's so quick to diagnose, that most of them are just seen as crazy – like schizophrenic or something.*  
(#11)

The health worker participants felt that psychiatrists were overly concerned with diagnosis and treatment of symptoms with drugs, and that this approach was not always helpful. Instead the health worker participants favoured early intervention by psychologists who were seen to take a more holistic approach, exploring and addressing underlying problems through counselling and advocacy. The Aboriginal health team described an innovative project to develop effective partnerships between Aboriginal health workers and mainstream general practitioners to assess and manage mental health problems in young Aboriginal people in the region[24].

Client/carer participants' understanding of mental illness varied widely, and seemed to be related in part to the clarity of health professionals' explanations and participants' ability to understand that information. It was apparent that some health professionals used language that was difficult for clients to understand.

*I've seen a psychiatrist yesterday, but then they're talking way over your head, you know. If you get an ordinary doctor, or get a doctor in that's willing to tell you in plain English, you're understanding what's going on. (#1)*

*I just couldn't really understand what they was talkin' about, you know, it was just going through one ear and out the other anyway. (#3)*

This sentiment was confirmed by the health worker participants who told how their roles included interpreting information for their Aboriginal clients and educating them about their health issues.

A perception voiced by one participant with a mental health disorder was that some doctors might not be interested in helping their patients to understand their illness.

*Yeah, it'd be good to know actually what it really is. I can't really understand my doctors anyway, you know, it's all big words. It's like they just want to talk just to get the money, you know. (#3)*

Participants' understanding of their illness appeared to be related also to their willingness to seek out health information.

*I like to read while I'm sitting there [in the health service waiting room] instead of just looking around so I just grab things and read them. (#2)*

One participant who had experienced a psychotic episode wanted to move on with life, and therefore did not actively seek information about it.

*I haven't really sat down with the doctor and asked her – said - ah - questions. And ah - But yeah, I just - I just try and forget about it all, so the quicker I forget about it, the quicker I'll heal. (#6)*

### ***The impact of the mental illness on mentally ill participants***

The impact of the mental illness on these people was severe. Feelings of shame, embarrassment and isolation were expressed by many client/carer participants. Some also spoke of strained and awkward interaction with their relatives and friends.

*First of all it was shame... I just locked myself in the room for years and years and years. I didn't leave my room, I didn't leave the house. (#2)*

*I had friends come in and see me in hospital... And made me feel - I don't know - fairly embarrassed, kinda thing. And I had this sheila, who I'd been seein' for a while, and she come in and seen me there and... Yeah, it's a bit of a shame job, ... to come and see me in a place like there. (#6)*

*There's a lot of shame in it you know like, because I don't talk to my friends or nothing about it you know. (#7)*

Similarly, the focus group of health professionals mentioned relationship problems, shame and depression, isolation, imprisonment and its ramifications, and financial difficulties as some of the problems experienced by people with mental health disorders.

### ***Impact of mental health disorder on family***

The health workers told how mental health disorders impact on the whole family of the affected person, and how family members seek help from them, including information, counselling, practical assistance and advocacy. However, most of the mentally ill participants had no awareness of any negative effects of their illness



on other family members' health and wellbeing. Indeed several mentally ill participants stated that their mental health disorder had little impact on the family. No-one mentioned loss of employment or education opportunities or the financial drain on family resources. The expectation that families will care for their mentally ill relatives whenever necessary was accepted by the carers.

*Nine times out of ten, they send them home to their family, you know ... families wouldn't turn them away. But you know, families get worn out too. (#1)*

Similar feelings were expressed by a carer about looking after a mentally disturbed relative's children.

*It's natural thing for me. They're my concern. Even though they mightn't be doin' me any good like 'ealthwise. (#8).*

Although not explored in depth during interviews with clients and carers, mental health disorders clearly had a great effect on the emotional wellbeing of families. This was usually not articulated, but seemed to be accepted with stoicism. One carer told of repeated verbal abuse and threats from a mentally ill relative, particularly after a drinking bout.

*Quite often when he's not well, he'll threaten me, when he's drunk, he'll threaten me, he threatens me and [name] quite often. ... "I'll bash you , I'll do..." and we just keep him back. But I say one day you know that might start and he might do it, who knows. I mean, he wouldn't do it intentionally, but he does get that way, gets really angry with – but he comes home from drinking and he gets really angry, and he'll – er - he doesn't hit us, but he'll abuse us. You know we've got ... kids here and he'll abuse us, the kids are asleep, and he'll wake them all up, you know. He's hopeless when he's on the drink...Next morning he's a different person altogether. (#1)*

Another participant with mentally ill family members had experienced negative impacts of their illness, including stress, verbal abuse and blaming.

Both women with mental health disorders acknowledged the negative impact of their illness on their children. One had to relinquish a child because her illness was so severe that she could not care for it. These women said that they did not want their children to see them in a very disturbed state or dependent on medication.

*I have always said that I don't want my [kids] seeing me going into a psychiatric ward because its not fair on them. (#2)*

*I used to wake up every mornin', "Where's my tablets, where's my tablets?" I didn't want my kids to see me like that. (#5)*

One positive impact of mental health disorders on the family was mentioned by a participant with a mental illness who returned home to recover. The participant told how the family had become closer, and now ate decent evening meals together rather than just getting take-away food, and how this would benefit the health of family members.

***Police attention as a result of mental health disorder***

Most client/carers participants did not talk about police attention as a result of mental health disorders. However, several mentioned that they had called the police or the Assessment and Crisis Intervention Service (ACIS) for help in emergencies, eg:

*When I get low, I'll ring up, always ring up with the police, I can't get any [medication]. Cos I'm frightened I'll hurt myself. But I always do that. (#5)*

*I tell them that I'm a schizo, I tell them I'm suffering from bipolar, I've got a mental illness, can ACIS come round and bring me some tablets. There's a team called ACIS, and they go out and get it out to the Aborigine guys here. (#5)*

Participants said that police were polite and helpful in such circumstances. Others called ACIS directly in such situations. Those who called on these services for emergency assistance were generally satisfied with them. However, one carer felt that the use of locked police vans for emergency transport of her mentally ill relative to a psychiatric hospital was inappropriate.

*He's sick, he's not a criminal, you know. (#1)*

One carer expressed a reluctance to involve police in a mental health emergency.

*I haven't got to the stage of ringing the police. Very nearly got into the stage of ringing the police for them, and you know, you think twice, you don't want to get 'em, police come and pick them up. (#1)*

***Factors that make the mental illness better or worse - medication***

The carers said that the symptoms of mental illness worsened markedly when prescribed medication was stopped, and improved when medication was resumed.

*He can go good for a while, and then he'll think that he's well, and then he won't take his medication, and then he'll break down. (#1)*  
*[Name] travels around a bit, and he might miss his needle, or he just came back the other day and he was very agitated, and he was a week over having his injection. So, we know he's had it [now], cos he's as okay as a fish today. (#1)*

The focus group of health workers also spoke of the tendency of some people to stop taking their medication when they felt better.

However, most of the mentally ill participants also acknowledged that the prescribed medications made them feel calmer, eg:

*The medication that you get – times you get the - throw things – smash things ... get a bit stressed out – just relaxes you more. (#3)*

***Factors that make the mental illness better or worse – alcohol, marijuana and tobacco***

Alcohol, marijuana and tobacco were named by many participants as substances that either exacerbated or ameliorated mental illness symptoms. Some participants believed that alcohol and/or marijuana were involved in the onset of their mental health disorder and therefore avoided them, fearing a relapse.

*Too scared to [have a beer]. In case I buzz out again or something. (#6)*  
*Others were making efforts to stop smoking marijuana and drinking alcohol on medical advice.*

*I gotta keep off the drink an' the dope an' that. But I smoke a little bit of dope. (#9)*

*I am surrounded by alcohol and smoke and marijuana. It's a hard way of living but I don't want to drink, the temptation is there all the time but I think that if I drink I'll have nothing. (#2)*

However many participants felt that alcohol and marijuana helped them to cope with their mental health disorder.

*Yeah, I smoke my [marijuana] pipe. That's good, that helps me stop hearing the voices, cos I hear voices too, and it stops that.*  
*...Because I have a smoke in the morning, to get me going... It doesn't affect me much, I tell you. (#5)*

Another participant with a mental illness who smoked marijuana habitually for many years expressed the belief that it was a more effective tranquilliser than prescribed medications. This participant felt that sudden withdrawal from alcohol and marijuana could exacerbate mental health problems.

*Well that's it see I've gone through the horrors you know like I smoke and drink for a couple of years and then when they lock me up in the psychiatric ward like you go cold turkey cos you're in a place where you can't go buy a beer over the counter or you can't have a cone you know. And like they keep you there for three or four weeks and your body's withdrawing from it you know. (#7)*

Tobacco was used by a number of participants as an aid to relaxation.

*What [tobacco] does is it relaxes me, mainly at night when the kids are asleep then and it's like a relaxant, like a herb to me, it relaxes me. (#2)*

***Factors that make the mental illness better or worse - family and friends***

The company of family and friends helped several participants cope with their mental illness. For example one person valued a sister's support during periods of depression.

*But my ...sister has been there for me you know, out all my family it's been my ... sister that's been there for me. (#7)*

Several mentally ill participants acknowledged the support of their families. Others felt that isolation made them feel worse and that simply chatting with friends helped them cope.

One mentally ill participant with young children said that her parenting obligations gave her the will to manage her illness, avoid alcohol and other drugs, and interact with the community.

*My [kids]s, they keep me strong mainly, my mother, yeah mainly my family. (#2)*

*I think that if I drink I'll have nothing, and I won't have my [kids]. (#2)*

*My [kids] make me do a lot of things, go to kindy, go to the school, mix with the teachers, mix with parents of the kids, they made me get out. (#2)*

*My [kids], they drive me crazy, but they give me something, I can't explain it but they make me do things, they make me be strong. They make me not want to be the depressed mother and I have always said that I don't want my [kids] seeing me going into a psychiatric ward because its not fair on them. I have to keep myself strong and if I need help its just on the end of the phone. Its so easy, why go stupid and end up in a psychiatric ward, I don't want my [kids] seeing me like that and then they have to leave you and that's very hard. (#2)*

***Factors that make the mental illness better or worse – professional counselling***

Talking over problems with health professionals was also beneficial for some participants with mental health disorders during stressful times.

*When I get stressed out here, at home, you know, and that's with my family because of their mental illness and I do go over there and talk to [name] the counsellor or the doctor, because I have to, because I feel as if the medication isn't doing any good for me. I go over there to get reassurance and then they talk to me calm me down and make me feel better. (#2)*

The health worker participants also spoke of the value of helping mentally ill clients to deal with their underlying problems.

### ***Carers' coping mechanisms***

One carer coped with the burden of looking after her mentally ill family members with a positive outlook and music.

*I won't let my mind, myself, think of anything destructive (#8)  
And talk about depression – oh, I just put my tapes on and sing  
some songs, and I'm back up again! (#8)*

### ***General health of participants***

The general health of participants with a mental health disorder at the time of interview varied. Several mentioned that they had other health problems such as diabetes, asthma and chronic headache. Similarly, the health workers reported that many of their clients were living with multiple health and social problems, including diabetes, renal failure, substance misuse problems, brain injury, homelessness, isolation, domestic violence and sexual abuse.

Some mentally ill participants self-managed their health effectively, eg:

*I look after myself because I don't want to get sick, I don't want to go to hospital. I have been a diabetic for [many] years... I just control it with what I eat and I don't take nothing (#2)*

Other participants did not manage their health problems so well, eg one person with a mental health disorder had severe recurrent headaches but had not discussed them with the doctor and took large amounts of paracetamol each day. Another suffered asthma but did not take medication prescribed for it:

*I just cope with it the best way I can (#7).*

Some participants mentioned recent elective surgery and self-inflicted injury, whereas others were relatively fit and well apart from their mental health disorder. Fitness training with a view to involvement in organised sport was important for two of the younger male participants.

### ***General health of carers and other family members***

The carers, who were both older women, had significant physical health problems of their own (cardiac and respiratory illnesses, diabetes). The general health of other family members was not much explored during interviews. One participant talked about her children's hearing and speech problems. The interviewer's notes/comments suggest that several participants had close family members with significant physical health and substance misuse problems.

It is notable that several mentally ill participants said that other family members had mental health disorders too. Both carers interviewed had several people with a mental health disorder and/or substance misuse problems in their direct care. The focus group of health workers also told of families in which up to five people were suffering mental illness.

## Medication

### *Types and sources of prescribed medications*

The participants had been prescribed a variety of medications for their mental health disorders. Medications were generally in the form of tablets and/or periodic injections. Many participants did not memorise the names or dosages of their medications, and one referred to them by colour and size. Several commented that they had been prescribed many different medications over the years.

Prescriptions were usually obtained from general practitioners, the South Australian Mental Health Service, hospital clinics or Brady Street Nunga Centre and filled at local pharmacies. Most participants with mental health disorders were responsible for obtaining their medications themselves, but several were taken to clinics for injections and tablets were dispensed at the same time. Others talked about medications being delivered to their homes.

*We know the nurse that comes around, yeah, and she – and SAMHS provides the medication for us, so they bring the medication here. And it's put out in their boxes, you know those little boxes, separate boxes, and that's each day, and each time they have to have them. (#1)*

### *Feelings about having to take medication*

Several mentally ill participants felt shame about having to take medication for their mental health:

*There's a lot of shame in it you know like, because I don't talk to my friends or nothing about it you know. Like that I have to have pills or whether I'm on pills. Do I have an injection, like, its just not talked about you know, like because of shame. (#7)*

Other feelings about taking medication included anger and annoyance, particularly for those on long term treatment.

*Oh it's really shit. (#9)*

*At first I think she was a bit angry, I s'pose, is the word that you're looking for. (#8)*

*Well, I don't know, just get pissed off at times and I don't want to [take medication], but I have to, just to keep myself at ease. (#3)*

It was difficult for some participants to accept the need for medication as they had rarely been ill before.

*It's bad enough just taking Panadol when you've got a headache or stuff like there. I'm a fairly average kinda person, never get sick or anything, and ah I used to hate taking medication. (#6)*

Despite these feelings, most participants took their prescribed medication because they believed it alleviated their mental health disorder.

*Well, they're just to make me - easy, more to relax, makes it easier to understand myself at times. (#3)*

*Not nice to take tablets, but you know, you know that this is going to keep you on that level, you do it. (#1)*

Another spoke of her relief at finally finding the right medication:

*I have found a[n anti]depressant tablet that suits me that doesn't make me half doped up all time, walking around like a zombie. (#2).*

In contrast, another participant with a mental health disorder felt forced to take medication.

*I feel like I have to take pills and medication against of my own will. (#7)*

*Well, well if I refused to take [medication] they would put me on treatment orders you know. (#7).*

However there was a tendency to reduce or cease prescribed medication when feeling well, evident in these excerpts:

*He can go good for a while, and then he'll think that he's well, and then he won't take his medication, and then he'll break down. He doesn't understand that he's going to break down. I tried to tell him that - like I take tablets every day, and I said well you take your tablets too, at the same time, and that worked for a little while, but then he said, Oh, I feel really good. And I said, Yeah, I feel good too when I wake up in the mornings, but I still take my tablets, you know? But I haven't been able to get that through to him. (#1)*

*The majority of the time I would just throw [prescribed medications] straight in the bin as soon as I got them because I didn't think I needed them. (#7)*

Several had experienced a decline in their mental health after ceasing tablets, eg:

*I took myself off the tablet, and I got worse, and now I'm back on the tablets. (#5)*

*I know that with the Zoloft I take 100mg a day. I don't take them all the time, I take them and then I might not take them for 5-6 days and then I think I feel I am losing it and I go back on them. (#2).*

A mistrust of medicines and a lack of confidence in them was apparent in some interviews with people suffering a mental illness

*Pills aren't going to solve my problems you know. (#7)*

*In my mind ... I think the doctor knows best, but really I don't think the doctor does know best, do you know what I mean? (#2)*

The health workers agreed that some Aboriginal people are suspicious of Western medicines. They were keen to offer traditional methods of

healing, but funds were not readily available to access the services of traditional healers (Ngangkari), who are not always regarded as legitimate by mainstream services. One participant with a mental health disorder was disillusioned with the continuous alterations made to the type and dosage of medications prescribed by doctors and wanted an Aboriginal treatment.

*I get sick of it. I want to go on black medicine leaf, if there is any. I know in my heart there is some there. The community that will find something for us Aboriginal people to help us. 'Cos the white people, I'm not being racist, I know it might sound it, but it seems to me they give me - a whole lot, like- two years ago I was takin' 6 - 8 tablets a day. Now I'm down to 4 tablets a day. ... but in another 2 weeks time I'll be taking another 4, then another 4, that'll be 8. Then I'll be askin' a lot of questions. (#5)*

Interestingly, the Aboriginal health worker participants also spoke of a subgroup of Aboriginal clients who followed their doctors' instructions unquestioningly.

*A lot of our elders in the community have got so much faith in the doctors. (#11)*

### **Information about and understanding of medications**

Client/carer participants obtained information about their prescribed medications principally from their general practitioners, hospitals and clinics. Much of the information about medications was given at the same time as information about mental illness (see elsewhere in this report). Leaflets were mentioned, as well as printed information on the medication packages and inserts. Other sources of information included television and Aboriginal health services.

*I get some off the TV, I get information from off the health shows programs on the TV, but mainly from Nunkuwarrin Yunti because I'm over there mainly and looking at the pamphlets and everything's there, and reading up. (#2)*

One person also told how a group of acquaintances with mental health disorders compared notes about medications.

*And we actually compare with each other, you know. What's that like? What's this like? It does this, it does that. (#3)*

The health worker participants believed that most of their clients had little knowledge or understanding of their medications, what they were, why they were prescribed, when and how to take them. Members of the focus group told how they spent a great deal of time interpreting and reinforcing medication information for their clients, particularly traditional or transient people who have difficulty with English language or those with cognitive deficits. They believed that



doctors and pharmacists provided their clients with insufficient information about storage, side effects and interactions of medications. The health worker participants felt that doctors and specialists should take the opportunity to review and explain medications and explore wider health issues during all consultations with Aboriginal clients.

Interviews with Aboriginal people with mental health disorders revealed varied levels of knowledge and understanding about their prescribed medications. Most understood their doctor's explanations, although it was not clear from the interviews what they knew. Some participants indicated that they would be confident to ask doctors for more information if they wanted it. In contrast, others knew very little about their medicines, either because they preferred not to know, or because they did not understand the words used. The issues impacting on understanding of health information are discussed elsewhere in this report in relation to information about mental illness.

A need for more information about medications and for more simple explanations was expressed in several interviews with clients and carers. One of the carers had asked doctors for information but wanted more, particularly about the effects of medication and the expected time before medicines work. A mentally ill participant who had experienced worrying side effects wanted more information about the long term effects of the drugs.

*I'd like to know the side effects that its having on my heart, on my ah kidneys and liver and all that you know. Like on my body organs like because I know the medication, like it wears me down you know and so I know it must be doing something to my heart and liver and kidneys you know. (#7)*

No-one had considered talking to a pharmacist about medications for mental health disorders, although one participant questioned chemists about over-the-counter medicines for her children's minor ailments. Most described their interaction with the pharmacist as an impersonal and rapid business transaction.

*I just walk in there, pay for it and walk out. (#3)*

*No. Don't really talk to him. I just go there, put my prescription in, get my medication, pay for it and that, that's it. (#7)*

One of the health workers believed that pharmacies were intimidating to some Aboriginal people.

*A lot of these people don't trust chemists – um - bit of a shame job there. ...Because they're not served – they're not treated very well at the chemists. Oh not always, but, - and one of the reasons ... is that chemists these days do not just dispense medication. There's an expectation that you'll buy something else when you walk in there.*

*There are all these different things on display. And 'Ooh, we don't have the money for that,' because in fact they don't have the money. They're there just for their health, scrape up their \$3.25 or whatever it is for the script, and so in the pecking order of things, if somebody's there looking as if they're going to spend – I don't know, oh buy, say, a \$10 bottle of Benadryl and um some perfume and that sort of stuff, and that seems that that person will get served before someone who's just got a \$3.25 script. (#10)*

### **Side effects of medication**

Side effects of prescribed medication were mentioned in all interviews. Participants had experienced a range of debilitating side effects including stiffness, lethargy, movement disorders, headaches, cramps, dizziness and more, as illustrated by the following excerpts.

*Walkin' crooked, drivin' crooked, getting sore glands in my throat... big guts, you know, loose bowels in the back, something like that – side effects. (#5)*

*Ah. They said you might feel a bit dizzy, like lightheaded - which I have been feelin' since I've been on the tablets, I haven't really felt like myself, like – feelin' lazy and feelin' like, really slow, and I'm starting in basic terms, like a robot. (#6)*

*Stiff neck, cramps in the guts, cramps in the kidneys, legs ah going stiff and that you know, and it feels sometimes like my arm is there but there not there like I got something wrong with my wrists you know. (#7)*

Side effects were described as life threatening in some cases. For example one participant told of almost choking in hospital due to stiffness of the neck and muscle spasm which were side effects of prescribed medication.

Memory loss was attributed to medications.

*Then these white[man's] medicines – it's - I can't remember when I was 5, I can't remember when I was 13, what I did, because all these things, tablets are takin' away our memories. (#5)*

*You know, when I was in hospital– I was in there for two weeks– and I can't remember the first week, and I said – I lay in my bed at night time trying to think what 'appened during that first week, trying to remember what 'appened and I can't. (#6)*

A number of participants had experienced particularly unpleasant side effects of lithium, of which one was bedwetting.

*That's the lithium, now they have side effects. I wet the bed, I don't want to go on with them. Like I have a big big big sleep, and I get out of bed. It's a bit embarrassing to me when I wet the bed at my age, like I was two years old. (#5)*

Participants all said that their doctors had warned them of some side effects from the prescribed medication. However it was evident that participants experienced many other side effects that had not been mentioned by their doctors. It is unclear from the interviews how much information was given or understood about potential side effects and what to do about them.

*When I first went in, yeah, he's mentioned, yeah, he's said a few things, but you know it's hard to really understand all the big words, try to break it down, you know. Virtually just gotta listen to what they say, take what they give, and out the door. (#3)*

Some said they had consulted the doctor about troublesome side effects, and that the dose was subsequently adjusted to reduce the problem.

One of the health workers believed that many people who experience unpleasant side effects may cease taking medication rather than seeking help to get more appropriate medication regime, particularly if the possibility of side effects was not explained satisfactorily.

*They're given a [medication] regime and expected to stick to it, and if it's not working, well then, people stop. (#10)*

Health workers agreed on the need for professional monitoring to ensure appropriate medication for each client and to increase compliance.

### ***Other licit medications***

The participants with mental health disorders were generally not using prescribed medicines for health problems apart from their mental health disorder. Indeed most were otherwise well. One had diabetes which was controlled by regulating diet. Both carers were taking prescribed medicines for cardiac and respiratory illnesses.

Most participants did not use over-the-counter medicines on a regular basis, apart from one mentally ill participant who took large amounts of paracetamol for recurrent headaches.

*Yeah, well – I sorta get up now, I'll just pop a couple of Panadol before [the headache] kicks in, you know, I know what's going to happen...I take three, straight away. If it's still there I'll just take another three again ... It all depends if I've still got the headache, if it's still there, I'll keep on taking couple more. (#3)*

This participant had not discussed this with the doctor and was urged to do so by the Aboriginal research assistant who conducted the interview. It was unclear whether the participant was aware of the potential for liver damage from excess paracetamol.

The health workers had experience of some mentally ill clients who took prescription medicines that were not meant for them, such as antidepressants and sleeping tablets.

Several participants told how they were not accustomed to pharmaceutical remedies until they became ill. One of the carers described growing up with little exposure to or awareness of health problems or medicines, and how this was in part due to being brought up not to ask questions of elders.

### ***Alcohol, marijuana, and other drugs***

As indicated elsewhere in this report, several participants with mental health disorders had a history of misuse of alcohol or other drugs, and/or mixed with people who used these substances frequently.

*Oh I still drink and smoke today you know. ...Oh well like most of the Nungas I know smoke and drink. (#7)*

The focus group of health workers agreed that harmful or hazardous use of alcohol and other drugs was common in their community. They felt that drug and alcohol problems were often rooted in a desire to block out pain and trauma, grief and loss, boredom, purposelessness and isolation. They described a deepening spiral of family and community breakdown associated with these problems. However, they also pointed out that alcohol and drug abuse is a learned behaviour, and cited the negative effects of peer pressure, poor role models in the family and community expectations. Illicit drugs mentioned by health workers included heroin, amphetamines and marijuana. They also mentioned how habitual recreational use of drugs may increase as users become accustomed to them.

Mentally ill participants had been advised to give up drinking and smoking, and most had done so, or cut down. Only one mentally ill participant continued using large quantities of alcohol and various other drugs as well as prescribed medication.

*I like drinking alcohol, you know. If I have a coupla beers I black out – and next morning, I'll be told what I've been doing but still can't remember, you know. (#3)*

*Taken other odd things, you know, like, been offered a few other medications, you know, bit of a mixture at times. (#3)*

*At the time it seems all right, you know, because your body just relaxes, my mind does too. Aw, next day you wake and it's all the same again. (#3)*

According to the health worker participants the use of cocktails of prescribed medications, alcohol and illicit drugs is common.

It was acknowledged that alcohol in particular led to conflict, eg one participant with a mental health disorder admitted that alcohol contributed to forgetfulness and feelings of anger.

*I get a bit forgetful at times, get at times a bit angry, you know. (#3)*

The carers talked about abuse and threats of violence associated with misuse of alcohol and other drugs, eg:

*They're smokers and they're drinkers. Moselle, wine, anything from a bottle...And that's when we have trouble... There's no control. We can't control them. (#1)*

One carer was concerned that using alcohol might interfere with a mentally ill relative's compliance with prescribed medication.

*The only thing I'm wary of is that's she's starting to have a - alcohol again, you see, and er whether she'll stop taking her medication I don't know, you see. Because um if I ask her, she'll get angry with me. And so er I just hope that she's - you know, knows what she's doing. (#8)*

Marijuana was popular with many participants. Being readily available and widely used, it was regarded by many as relatively benign.

*[Doctors told me] that I gotta keep off the drink an' the dope an' that. But I smoke a little bit of dope. (#9)*

One mentally ill participant preferred marijuana to prescribed medication, believing it to be more effective and less harmful.

*Even one of my cousins said to me like look I've seen you on dope and I've seen you on them pills and he said to me I prefer to see you on dope than what them pills do to you, you know. (#7)*

The section of this report on factors that make mental illness better or worse explores marijuana, alcohol and tobacco use in more depth.

### ***Compliance with prescribed medication***

Most participants reported that medications were taken according to the directions on the packet. Compliance with the treatment regimen was enhanced by taking the tablets at set times, such as with meals, or on waking or retiring. Sometimes family members reminded participants to take their tablets. Participants who accepted the benefits of prescribed medication were generally careful to comply. The health workers noted that homeless or transient people often have difficulty complying with medication regimes, as they may not carry their tablets or prescriptions with them.

Few participants with mental health disorders used a dosette to organise medications for the coming days. Those that did generally had the dosette filled by a health professional during clinic visits. The health worker participants felt that more widespread use of dosettes or bubble packs would enhance compliance, particularly for confused clients, or those with dementia or other brain damage. Several participants with mental health disorders admitted that sometimes they did not remember whether or not they had taken a tablet, but most said they would not take a tablet just in case.

Participants were asked if they had ever deliberately stopped taking medications. Several had done so, but had quickly noticed a decline. Some participants admitted reducing or ceasing medication when feeling well, and this is explored elsewhere in this report. It is not clear whether the potential danger of sudden cessation of prescribed drugs was fully understood by participants, or whether health professionals had discussed this with them. One person described how blood pressure dropped to dangerously low levels after suddenly ceasing to take tablets.

*I don't like taking the Zoloft mainly because I read about it in the little pamphlet that you get in the box. I did go off the Zoloft, cut off, and it ended up my blood pressure went down to  $90/70$  and I didn't know what I was doing. I didn't even know that they were withdrawal symptoms from the Zoloft, just automatically cutting them off. See I left it too long that time and I got back on them and I'm alright, I just have to take them. (#2)*

Another mentally ill participant was mistrustful of medications and had suddenly stopped taking medications on several occasions, resulting in withdrawal symptoms, followed by an improvement.

*[I sometimes stop taking medications] because I'm against pills.... Oh well maybe at first [I feel sick]but after a couple of weeks of eating right and exercising and like drinking plenty of water I start to feel better you know. (#7)*

Participants with mental health problems said that they sometimes reduced the frequency of prescribed medications to make them last until the next payday or clinic visit.

*If I've got 5 [tablets left] and I've got a week to go...then I will take one every second day to get me through. There are 25 in the packet and when I am down to the last 5 and I haven't got any money then I will spread them out. (#2)*

Others simply went without medications if they ran out. The health professionals said they knew of clients who would take extra medication to make up for missed doses.

Client/carer participants were also asked about any times when more medication was taken than prescribed. This was rare, with most instances having occurred long ago in the context of a deliberate overdose. Only one person admitted increasing the dosage according to how the participant felt at the time.

*Just take another one, and that's all there is to it. Depends how my mind is, I suppose. (#3)*

Most participants said that they would not take more medication than was prescribed if they were feeling low, eg:

*Um - I suppose I'll just have my down days. (#9)*

### ***Inappropriate prescribing/dispensing of medications***

The health worker participants told how some patients took unnecessary or duplicated medications following discharge from hospital:

*A lot of them, as I said, [are] getting discharged with tablets from the [hospital] pharmacy, going home, they've got them all lined up in the cupboards there, it says, 'take one here', then this other tablet says 'take one', and they're exactly the same tablets but they're not being explained all of that, and that's where that overdosing ... occurs within a lot of our elder fellas because 'the doctor knows best'. (#11)*

The health workers talked about how difficult it is to address such problems because the Northern Metropolitan Community Aboriginal Health team has no formal link with the hospital pharmacies. They believed that health workers, doctors and pharmacists should work together to ensure that clients understood that they should discard their old medications in such cases.

Several cases were described where people with a mental health disorder were provided with very large amounts of medication. For example a carer told how her mentally ill relative, acutely distressed and already on medication, visited the clinic and obtained a large quantity of additional medications, subsequently overdosed and was rushed to hospital. The carer felt it was inappropriate to send a depressed and suicidal young person home with a large supply of drugs. She complained to the clinic, saying:

*That's not right, you know. A ... kid goes over there, telling you he's depressed, why didn't you get him in to see, you've got counsellors, why didn't you get him to see a counsellor as well? Or send him down to SAMHS would be good as well as giving him tablets. Why give him 500 tablets? (#3)*

Another participant described attending two hospitals within a week and being discharged with supplies of separate medications from each hospital, about 30 boxes of tablets in all. The participant did not want to take them, and threw most of them away. Each fortnight more tablets were delivered to the participant's home, and again usually thrown away. There was no follow-up to determine compliance or whether the medication was helping. The participant simply accepted them to avoid treatment orders.

### ***Storage and disposal of medicine***

Client/carers participants said that medications were stored out of reach of children, hidden in bedroom drawers or up high, but not in a locked medicine cabinet. They were confident that no-one else in the

family had access to the medications and that children in the household would not take them. Medicines were stored in their original containers, and repeat prescription sheets were generally kept with the medicines. Participants knew how to tell if medicines were expired or damaged. Most discarded out-of-date and unwanted medications into the rubbish bin.

### ***Stockpiling***

Most participants used up their medications before obtaining a fresh prescription, and so stockpiling was rare. However, some participants admitted keeping quantities of medicines at home for emergencies.

*Look, you know, what I do is that I just stockpile these medicines at home, I've got the biggest heap of them at home, and I just keep 'em there in case I need 'em. (#5)*

Stockpiling was more likely if medicines were perceived as hard to obtain. For example one person mentioned how difficult it was to convince the doctor to prescribe a sedative. Another kept a large store of tablets designed to counteract muscle aches and stiffness, side effects of the medication.

### ***Sharing medications***

According to the client/carer participants, sharing of medicines did not occur, with most being aware of the potential harm that could occur from sharing medications. One told how an acquaintance became stiff and dangerously short of breath after taking the participant's medicine without permission. The participant recognised the problem as a side effect of the medication, enabling prompt life-saving paramedical attention. Most people with mental health problems or their carers emphatically disapproved of sharing prescribed medicines. Only one participant admitted ever deliberately sharing medicines with peers. In contrast, the focus group of health professionals believed that sharing of all types of medications is common, including prescribed medication for mental health disorders, particularly among transient people.

### ***Cost***

Client/carer participants were all in receipt of some type of pension or benefit. It appears that some people obtained medications free, whereas others paid the minimum amount for their prescriptions. A figure of around \$3 per prescription was mentioned by one participant. Several participants were taking a number of medications, and so the cost of these items was a strain on a limited budget. As mentioned elsewhere, some people said they eked out their medications to last until next payday. One of the carers told of lending money to a relative to pay for prescriptions.



The focus group of health workers agreed that cost was a major issue for many of their clients. They told how some people had to obtain their medications from the public hospital pharmacy because it was possible to obtain the tablets and be billed later. However this meant many hours of waiting in the emergency department and formal assessment, which may not be possible when clients have other responsibilities. The health workers said they sometimes paid for clients' medication from their own pockets in such cases, as illustrated by this quote:

*Yeah, there was one not long ago that needed heart medication and was um ringing us to see if we had the money to pay for his medication, he needed two different sorts of medication. I had to get back to him, but, like, if you're going through the hospital, and they give you a script for medication at the pharmacy over there, they will let – they will bill you and send it out. But he had an outside medication, so – which meant that the hospital wouldn't take an outside medication, so what he has to do is go back to A&E, go through – get assessed and everything, get the script, and go. And he wasn't prepared to do that, yet he really needed his medication, but he didn't want to go sitting in there for another six hours like he did the week before. So um what happened with him was, we ended up getting money for his medication, but – out of our own pockets as well. (#11).*

## Health Services

### **Mainstream health and community services**

Mainstream services utilised by client/carer participants included South Australian Mental Health Service (SAMHS), psychiatric hospitals, other public hospitals with mental health facilities, mental health outreach services, Assessment and Crisis Intervention Service (ACIS), the Northern Metropolitan Community Health Service, local general practitioners and pharmacies.

Most participants with mental health disorders had seen health professionals in many settings, and told of having to repeat their story each time they saw another doctor.

*Yeah. The whole story, over and over. It's 'appened every time. I get tired of it. So I just sit back and wait, if they ask a question I'll tell 'em. (#5)*

There was a feeling of frustration and some had resorted to minimal conversation with their doctors.

*No, I just walk in and ask you know, he just asks me how I'm doing, I just tell him how I feel, and they give me a prescription, and I leave. (#3)*

In contrast, other participants had developed a good rapport with their health professionals and felt comfortable talking to them.

The health worker participants said that many of their clients, particularly those who were transient, did not visit a particular doctor or clinic regularly, and consequently had multiple, sometimes duplicated, medications. The health workers were concerned that the various doctors did not know what the others had prescribed, and the vulnerability of such patients to overdose.

Some GPs were known by participants with mental illness as *script doctors* (#2) who would write prescriptions without examining or questioning them. One participant spoke of having two doctors, one who monitored and prescribed medications for the mental health problem, and another who prescribed extra drugs *for a headrush* (#3) without asking questions. Health worker participants agreed that some people might visit several doctors to obtain other prescription drugs, but felt that this was relatively infrequent.

#### ***Aboriginal health and community services***

Services specifically for Aboriginals were widely used including Brady Street Nunga Centre, Nunkuwarrin Yunti and the Aboriginal Health Team at Lyell McEwin Hospital. The Aboriginal Sobriety Group was also mentioned. Interestingly, a number of the client/carer participants were unaware of these Aboriginal services, and relied totally on mainstream services. The focus group of health workers were from the Northern Metropolitan Community Aboriginal Health Team, which is part of the Northern Metropolitan Community Health Service. This Aboriginal Health Team was known to all the client/carer participants.

Several people expressed a desire for more Aboriginal services and supports in health and community services. For example a mentally ill participant wanted an Aboriginal doctor.

*I really like to go to an Aborigine doctor. (#5)*

A carer was concerned about the lack of Aboriginal-specific followup services for people coming out of hospital.

*You know? There's nothing for them. There's no place they can come, no place they can go. They can go to Midway Road, where they've got a little centre there, for people coming out of the hospitals, but they said, Oh we're not going over there, you know, they're all white people. There's no Aboriginal thing like that set up for them. (#1)*

This was echoed by the health worker participants who were frequently asked to help with hospital discharge planning arrangements for Aboriginal clients. They generally suggested

followup care from Brady St or recommended a doctor from a list of local general practitioners known to be sympathetic and respectful towards Aboriginal people.

The health workers' focus group argued that there was an urgent need to train more Aboriginal health workers to work in the community. Furthermore they called for an increase in the number of Aboriginal doctors, social workers, services, counsellors, liaison people in all mainstream services to deliver culturally appropriate care. They spoke of the reticence of some Aboriginal people to use mainstream services where they are likely to be stereotyped and labelled. The health workers knew of people who had discharged themselves from hospital because of rudeness and discrimination, and how they wanted members of the Aboriginal Health Team to accompany and advocate for them on their next hospital visit. According to the health worker participants, some Aboriginal people are ashamed to go to mainstream health services, especially if they have been abused and have physical injuries.

When discussing a need for mentally ill people to talk about their problems a carer suggested that Aboriginal clients would be more likely to talk openly with Aboriginal counsellors than with white people.

*I don't think they'll speak in a – in a hospital because it's all – all Goonyas, and white fellas. But if they um - if there was Aboriginals going in there that they made friends with, or knew, I think it wouldn't be too hard for them to open up. (#1)*

Several participants said they appreciated the fact that the interviews for this project were conducted by an Aboriginal researcher.

#### ***Gender-specific and age-specific services***

None of the clients or carers interviewed knew of services aimed specifically at men. One mentioned a women's health centre that she had used in the past. Only one female participant with a mental health disorder expressed a particular need for gender-specific services. She said she had great difficulty talking to white males, and would be more comfortable taking to a woman or an Aboriginal person. However the worker participants said that mental health services aimed at men, women and youth were sorely needed in the Northern metropolitan region. In particular, there is nowhere for youths under 18 years to go in a crisis after hours.

#### ***Drug and alcohol services***

Drug and alcohol services named by client/carers participants included Brady Street Nunga Centre, Aboriginal Sobriety Group, and Warranilla.

However most did not know where to go for help or information about drug and alcohol problems, although one thought that information might be available from chemists, medical centres, welfare offices and schools.

One of the carers would have liked her mentally ill relative to be compelled somehow to address drug and alcohol problems, but understood that this had to be the relative's own decision.

*I asked about could there be an order put on him to - so he stops with the drugs and alcohol, or he goes, he goes and has some kind of treatment, and they said they can't do anything because it's a personal thing. But he needs to ask for that himself. (#1)*

#### **Respite care, home help, etc**

None of the client/carer participants had ever had any respite care. This included the carers who had been looking after their mentally ill relatives for many years, and mentally ill people with family responsibilities.

*I've never had respite, never. (#2)*

The health workers confirmed that many carers do not know that respite could even be a possibility.

One person with a mental health problem had been attended by a district nurse at home for post operative care. Some had limited help with daily living at home. Another had some assistance from a community service group with social activities, but was unaware of any other sources of help.

#### **Support for carers**

Although no complaints were voiced by the client/carer participants, it was apparent that money and resources were in short supply, and practical assistance was nonexistent, making each day a struggle. The carers had no access to respite care, which added to their burden. This is significant given that both carers interviewed were elderly women with severe health problems of their own and considerable family responsibility. The health workers agreed that carers are in great need of support. They told how carers are expected to look after their relatives, and of the difficulties this posed, particularly in families in which several people had mental health problems.

#### **Access to health and community services**

Most client/carer participants relied on public transport and walking to get to these services. Some were provided with transport to attend clinics, and this was appreciated. Carers had no help in reaching services which caused them difficulty, particularly when visiting hospitals far from home.

The health workers frequently mentioned the need for more transport assistance for their mentally ill clients.

*They won't access any services – if they can't get there, they just won't ... there are some people that just don't know how to get there unless we pick them up. (#11)*

The focus group of health workers described how mainstream providers misunderstood the role of the Northern Metropolitan Community Aboriginal Health team in providing transport for Aboriginal clients. The Aboriginal Health team has traditionally provided such help when there is no alternative, but it was perceived that this practice has been taken for granted and is sometimes used inappropriately by mainstream providers.

*We can't say no to our own, you know, that's how we are. But you know... the erm mainstream organisations are seeing that ... [the] Aboriginal Service ... they'll do it for their people ..., so you know... it's like a bit of a guilt trip you know? – like if we don't do it, they ring up and put the pressure on us (#11)*

#### ***How do participants know about the services***

Client/carer participants said they found out about health and community services themselves and by talking to their peers. Some admitted that they did not know how or where to access services:

*Oh – I know there's a few [health and community services] around – but there's – you know – no direction, I don't know where they all are. (#3)*

#### ***Satisfaction with services***

Participants' satisfaction with services varied considerably. A number of negative experiences were recounted, many of which have been discussed elsewhere in this report.

Problems included discrimination and rudeness, misdiagnosis of other health problems, dislike of particular doctors, inappropriate dispensing of medication, and inadequate supervision. One participant absconded from one psychiatric hospital and was not missed for five days, with the absence only becoming apparent after a telephone call advising that the participant was in another hospital.

However, several participants were quite satisfied with the health services they had received, or had eventually found service providers who met their needs. Services that were particularly appreciated by those fortunate enough to receive them included transport assistance to clinics, free medications, dispensing of medications in dosettes, prompt help from ACIS and referrals by general practitioners to specialists for other health problems. A number of participants praised particular services, eg:

*When you go to Brady street they always up to speed, they know all about you and what you're on about. (#2)*

*Yeah. I go through them guys and I reckon they're good. (#5)*

*I like my GP down the road, he's alright you know. (#7)*

### **Coordination of services**

A number of examples of poorly coordinated services were discussed in the interviews. General practitioners and health professionals in clinics and hospitals were not always aware that they were simultaneously treating the same person. Sometimes this had potentially dangerous consequences such as multiple prescribing and conflicting advice, as described elsewhere in this report.

Health workers were passionate about the need for better coordinated and more equitable resourcing of services. They wanted better links and communication between mainstream and Aboriginal health services to enable more effective service delivery. Currently mainstream service providers call on the assistance of the Northern Metropolitan Community Aboriginal Health team whenever there are problems with Aboriginal clients, leading to overstretched resources and pressure on staff. They wanted to be notified when Aboriginal clients from their area accessed mental health services so that they could arrange and coordinate ongoing support. The Northern Metropolitan Community Aboriginal Health Team was aware that acute care hospitals receive a 30% casemix loading for each Aboriginal client [25]. They felt that there were opportunities to use these funds creatively to improve Aboriginal-specific services. For example, allocation of a portion the money to the Northern Metropolitan Community Aboriginal Health Team would assist them to provide transport, arrange followup, assist with discharge arrangements and so on for Aboriginal clients.

## **Discussion**

The interviews analysed here provide a rich insight into the experiences and views of Aboriginal people with mental health disorders, their carers and health workers in relation to medication use. It seems that some people cope with their mental health disorders and manage their medications quite well, and that the Northern Metropolitan Community Aboriginal Health Team provide support and care beyond the call of duty. However it is also evident that medications are not always used safely or optimally, potentially putting some people at risk. Many Aboriginal people with mental health disorders, their carers and other family members are struggling to cope with multiple and complex problems in their lives and are not always receiving adequate or appropriate support. The major issues to

emerge from this research centre around:

- poverty
- shame
- understanding of mental illness and medications
- coordination of services
- adequate and appropriate services
- the relationship between alcohol or other drugs and mental illness
- burden on carers

## Poverty

There is a well known association between mental illness and socioeconomic disadvantage[5, 26-28]. It is also well known that Aboriginal people are among the poorest in Australia today[4]. Therefore, being both Aboriginal and mentally ill confers a double disadvantage[29, 30]. Poverty was an underlying theme in the interviews, though rarely articulated directly. The client/carer participants were all living in very modest circumstances, none were in paid employment and all struggled to get by on welfare benefits of some kind. Shortage of money meant that some people delayed buying medication, or eked out medication until the next payday. Poverty may lead people with mental illness and their carers to deprioritise the purchase of medication and other health-related expenses compared to immediate essentials such as food and rent. Solving immediate problems which impact directly on life, eg reconnecting the electricity, mediating a dispute, obtaining emergency funds, was considered to be more important to most Aboriginal people than buying medication. The prevailing view expressed in this study was that serious and sustained efforts must be made at high level to address socioeconomic disadvantage among Aboriginal people as a priority, otherwise specific strategies to achieve quality use of medications would likely be ineffective. Similarly, others have called for commitment to improving social and economic status of Aboriginal people as a necessary first step in achieving quality health outcomes[5, 27, 31]. This study also identified difficulties with transport and access to services, and the burden this placed on the Aboriginal Health Team, which also relate to poverty.

Furthermore, limited resources, complex funding allocations, lack of clarity about money flows between services and confusing subsidy arrangements contributed to the financial pressure experienced by the Northern Metropolitan Community Aboriginal Health Team.

## **Shame**

Shame was another theme which threaded through all interviews. Some participants with mental illness were ashamed of their condition and ashamed that they needed medication. This inhibited them from seeking information and medical assistance for their condition and/or their medication issues. Health workers talked about the tendency of some Aboriginal people to put on a brave face and carry on despite grief and loss and family breakdown, and how their clients felt shame at having to admit they needed help, sometimes turning to alcohol or other drugs in an attempt to block out their pain. Although the need for strategies to destigmatise and raise public awareness about mental illness, including specific programs for Aboriginal people, has been identified[32-34], negative attitudes and shame about mental health problems remain widespread in the Northern metropolitan Aboriginal community.

Some doctors misinterpret manifestations of shame, eg shyness and reticence to talk, and misdiagnose or fail to explore underlying issues. It was clear that Aboriginal clients felt more comfortable with Aboriginal health professionals. Development of partnerships between Aboriginal and non-Indigenous health workers, and cultural awareness training for mainstream service providers have already been recommended and piloted[24], and need to be extended and sustained in the Northern metropolitan region. These would facilitate respectful trusting relationships between Aboriginal clients and health professionals, lead to earlier identification of mental health problems and issues underpinning them, and enable prompt and appropriate referral to services such as the stolen generation team or drug and alcohol services. The consensus was that such initiatives could prevent mental health crises and consequent medication management problems.

## **Understanding of Mental Illness and Medications**

Understanding of mental illness and medication varied widely, confirming previous research[27]. It is evident that most people with mental health problems and their carers wanted more information and clearer explanations in language they could understand. The Aboriginal Health Team spend a lot of time interpreting and reinforcing health information for their clients. This study showed that many clients did not understand their medications, the importance of compliance with the regime and potential side effects, a common problem in many populations[35]. However, it was agreed that better understanding of mental illness and medications may not necessarily translate into improved compliance unless more pressing problems with daily living are solved first.



It appears that traditional Aboriginal understandings of social and emotional wellbeing and mental illness, causes of mental health disorders and traditional approaches to healing have been largely disregarded by mainstream health professionals. It was not surprising that there was some mistrust of psychiatric diagnoses and drug treatments by some clients and health workers. These findings confirm previous reports[36, 37].

## **Coordination of Services**

Poor coordination of health services was a major issue to emerge from this research. Many examples were given of patients receiving treatment and advice from several doctors or clinics, without adequate communication between them, leading to unnecessary prescribing, conflicting advice and potentially dangerous consequences for clients. Doctor shopping for drugs is easier if services are poorly coordinated. Transient people, or those without Medicare cards tend to visit doctors or clinics convenient at the time, highlighting the importance of better service coordination. The Northern Metropolitan Community Aboriginal Health Team wanted improved communication from hospitals and clinics to enable them to provide more efficient followup and support activities. Although guidelines have already been developed to facilitate continuity of medication management between home and hospital[38], it appears that communication breakdowns still occur. The Aboriginal Health Team is currently spending much time and effort providing services such as transport that could be arranged by other agencies, putting pressure on their staff and resources. Finally, integration of health and other social services, eg housing, justice, welfare, social work is lacking. There are many published articles calling for integrated intersectorial responses to problems faced by Aboriginal people[39, 40]

## **Adequate and Appropriate Services**

A number of examples of racial discrimination, stereotyping and lack of cultural awareness were given. At the same time many participants were very satisfied with their treatment by Aboriginal health workers and services. It is clear that there is an urgent need for more Aboriginal service providers across all health-related portfolios and institutions, because many Aboriginal clients prefer not to go to mainstream services. There is also need for mainstream service providers in northern Adelaide to become more culturally aware and to modify their practices, as demonstrated elsewhere[41]. Furthermore, the Northern Metropolitan area has inadequate gender-specific, age-specific services, and drug and alcohol services.

Appendix 2 provides more information about culturally appropriate service provision, including underlying principles and indicators, based on the literature[3, 29, 42-46].

## **Relationship Between Alcohol or Other Drugs and Mental Illness**

Several participants believed that their mental illness was caused or triggered by excessive use of alcohol or other drugs. Health workers agreed that harmful or hazardous use of these substances was sometimes associated with the onset or worsening of mental health problems. Literature shows that long term alcohol abuse damages the brain, leading to mental disorders such as alcohol-induced dementia[47, 48]. Similarly other substances such as solvents damage the nervous system. Prescribed drugs for common physical illnesses may also result in confusion and cognitive impairment[49]. However, it was also evident that social dislocation, family breakdown, grief and loss issues, and other life events were involved in the onset of mental health problems among Aboriginal clients in Adelaide's Northern suburbs. Genetic factors could also be involved as there were a number of families mentioned in which several members had mental health problems.

Alcohol, marijuana and other illicit drugs are frequently used as an escape or coping mechanism to mask underlying mental health problems and social and emotional distress. A culture of acceptance and promotion of drinking and drugging in some sectors of society was highlighted by health workers. A number of participants told of difficulties in avoiding these drugs in such an environment. There is a need for more creative prevention and diversionary schemes, education and supports to minimise harm, and positive role models to reduce inappropriate use of these substances. Withdrawal from addictive substances, for example during detention in prison or hospital can exacerbate mental and emotional distress, and clients are at risk of overdose on discharge[50].

Domestic violence was another theme which threaded through the data. Mental illness may cause behavioural disturbances, but medications were a calming influence. Participants spoke of violence and agitation when compliance was poor. They were particularly concerned about escalating violent or abusive behaviour following excessive drinking. Mental illness is linked to domestic violence, both as a contributing factor, and as a consequence[51]

## **Burden on Carers**

Aboriginal carers are invariably family members, often older women with significant health and social problems of their own. The expectation of society in general and Aboriginal families in particular is that family members will care for their relatives. It appears that the resilience of many Aboriginal carers, and their apparent willingness and ability to take on ever more responsibilities may be taken for granted. There is an urgent need to provide support to these people, as the burden on their lives is crushing. In particular respite, transport, information, and financial help are desperately needed.

## **Recommendations**

The following recommendations were developed collaboratively by the Research Team and the Northern Metropolitan Community Aboriginal Health Team after significant deliberations on the draft findings. A focus group, face-to face and virtual meetings were devoted to developing these recommendations. Some recommendations are broad recommendations addressing socioeconomic disadvantage, institutional racism and inequities in service provision, since these factors underpinned many of the medication management problems of Aboriginal people with mental health problems. Others are specific to medication issues or local concerns.

### **Recommendations**

1. That effective and multifaceted programs to address poverty and its root causes among Aboriginal people be implemented and sustained.
2. That health services and health professionals ensure that their practices and policies are culturally appropriate. Suggested strategies include:
  - cultural awareness training and support for non-Indigenous GPs, nurses, pharmacists and other mainstream health workers;
  - ensuring mainstream health professionals are educated about Aboriginal understandings and manifestations of health/illness, social and emotional wellbeing, and traditional approaches to healing;
  - dissemination of current referral information for a range of services relevant to Aboriginal social and emotional wellbeing issues (eg schemes to reunite families);
  - employing more Aboriginal workers across all health and social services in the northern metropolitan area of Adelaide;
  - clarifying, formalising and promoting systems for recognition and payment of traditional healers (Ngangkari).

3. That culturally appropriate information about mental health issues be made widely available to the Aboriginal community in order to:
- raise awareness and understanding of social and emotional wellbeing issues;
  - destigmatise mental illness;
  - increase understanding of the different roles of health professionals (eg psychologists, counsellors, psychiatrists, traditional healers), mainstream and alternative treatments;
  - encourage people to seek help;
  - increase general understanding of medications for mental illness, including purpose, safe use, compliance, interaction with other substances, side effects, storage and disposal.
- This information could be provided in multiple forms (eg brochures, posters, videos, stickers) and locations (eg health centres, pharmacies, community centres, sports clubs, schools).

4. That a range of culturally appropriate early intervention strategies for Aboriginal people with social and emotional wellbeing problems be developed and promoted. These might include peer group counselling and community support groups.

5. That integrated health service delivery systems be developed in the northern metropolitan area. Suggestions relevant to medication management include:
- adopting a regional approach to health service delivery and planning, involving hospitals, emergency departments, GPs, pharmacies and the Northern Metropolitan Community Aboriginal Health Team;
  - Aboriginal and mainstream health services in the northern metropolitan region together developing an equitably resourced system for distributing medications to those who cannot afford them;
  - using additional funds allocated to GPs through the Aboriginal Primary Health Care Access Program to provide extra consultation time with Aboriginal clients for provision of appropriate explanations and information about mental health and medications;
  - developing and implementing effective communication systems between health services, eg a simple interagency computer network. These systems should enable service providers to track individual clients so that overprescribing and conflicting advice is minimised, while preserving confidentiality;
  - developing and implementing systems for effective coordination of health and other service providers. In particular, better linkages between health services and

- correctional, educational, employment and social services are required; and
  - fostering and strengthening collaborative networks of workers across health and social portfolios (eg Aboriginal Workers Forum and the Northern Interagency Group).
6. That all workers providing assistance to Aboriginal people with mental health problems and requiring medications have access to professional training about:
    - social and emotional wellbeing issues in Aboriginal communities;
    - mental health problems;
    - alcohol and other drugs; and
    - safe management of medications.
 These topics should be included in curricula for Aboriginal health worker education programs such as the Certificate in Aboriginal Primary Health Care.
  7. That gaps in service provision for Aboriginal people in the Northern Metropolitan area of Adelaide be addressed. In particular there are identified needs for:
    - health services for Aboriginal youth;
    - gender-specific Aboriginal health services;
    - health services for older Aboriginal people; and
    - drug and alcohol services for Aboriginal clients, eg substance misuse clinics, harm minimisation schemes, health promotion activities and positive role modelling in schools and community groups.
  8. That Aboriginal family members who care for people with mental health problem be supported in their role and recognised for their contribution. In particular, respite schemes, transport assistance and financial support are urgently needed.
  9. That support and skills development be made available to Aboriginal clients in budgeting for medications.
  10. That pathways be developed to for supporting quality use of medications by
    - Aboriginal elders on discharge from hospital; and
    - Aboriginal prisoners with mental illness on and after release, eg by strengthening and formalising links between correctional services health staff, health workers on the outside and families.

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## **Appendix 1. Steering committee**

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**Lynette Cusack**, Drug & Alcohol Services Council  
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**William Donahue**, Hepatitis C Council  
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**Zell Dodd**, Community Development and Primary Care, Department of Human Services  
**Sue Foster**, Director of Country Services, Department of Human Services  
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**Isabelle Norville**, Chairperson, Aboriginal Drug and Alcohol Council (SA) Inc.  
**Warren Parfoot**, Aboriginal Drug and Alcohol Council (SA) Inc  
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**Cephus Stanely**, Pika Wiya Health Service  
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## **Appendix 2.**

### **Culturally appropriate service provision**

Throughout this document the term ‘culturally appropriate’ has been used, encompassing notions of cultural safety and cultural competence. The following indicators and principles for culturally appropriate services are drawn from contemporary sources [3, 29, 42-46].

Indicators of cultural appropriateness of an individual service will vary depending on the characteristics of the Aboriginal community it serves and the nature of the service. Indicators of culturally appropriate service include:

- Accessibility
- Proven responsiveness to Indigenous people.
- Delivery of high quality services that effectively meet identified needs of Indigenous people.
- Culturally appropriate service provision, eg attention by nursing staff to Indigenous language needs.
- Adequate resources and commitment to introduce and sustain culturally appropriate service models.
- Accountability
- Coordination and ongoing planning in consultation with legitimate community representatives
- Acknowledgment of traditional and customary law
- Acknowledgment of gender and seniority issues.

Culturally appropriate services are based on the following principles

- The Indigenous concept of health is holistic and encompasses, mental, physical, social, cultural and spiritual health.
- Self determination and empowerment of Indigenous people’s social justice issues is recognised and is paramount.
- Culturally valid understanding must shape the provision of services.
- Experiences of trauma and loss are major factors contributing to impairment of health and wellbeing. (ie stolen generations, family loss, institutional racism, and incarceration.)
- Human rights of Aboriginal people must be recognised and respected.
- Racism, stigma, environmental adversity and social disadvantage continue to have a negative impact on health and wellbeing of Aboriginal people.
- Family kinship is central to social and emotional wellbeing.
- There is great variety in culture of different Aboriginal groups.
- Aboriginal people have great strengths.





