

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

*Report on research conducted  
in the Port Lincoln region*

P O R T L I N C O L N



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)*

medication  
management  
aboriginal people

# **Better medication management for Aboriginal people with mental health disorders and their carers - Report on research conducted in the Port Lincoln Region**

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Port Lincoln Aboriginal Health Service hosted the project in Port Lincoln.

# **Better medication management for Aboriginal people with mental health disorders and their carers - Report on research conducted in the Port Lincoln region**

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

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# Executive Summary

## Introduction

Grief and loss, chronic poverty, social dislocation, lack of culturally safe services and long term cultural disruption continue to affect the health and wellbeing of Aboriginal Australians. The latest statistics indicate that the Aboriginal population is still much sicker, younger and poorer than the non-Indigenous population. Mental health disorders (problems of social and emotional wellbeing) are widespread among Aboriginal people, and often complicated by other chronic illness and/or substance misuse. Quality medication management can be difficult for many Aboriginal clients, 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.

This paper reports on research conducted in Port Lincoln during 2001-2. It 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.

## Aims and objectives

- 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.
- To recommend strategies to improve quality use of medicines by this group, informed by the findings.
- To implement and evaluate selected recommendations.

## Participants and methods

The host organisation for this component of the SA-wide project was Port Lincoln Aboriginal Health Service (PLAHS). A local steering committee of Aboriginal and mainstream mental health service providers, general practitioners, pharmacist, community workers and other key stakeholders guided all aspects of project in the region. Data was collected from semi-structured interviews and focus groups with Aboriginal people with mental health disorders, carers and health workers. All participants were drawn

from the Port Lincoln area. Verbatim transcripts were analysed to identify common themes and important issues. Recommendations were developed collaboratively with health workers and the steering committee, supported by other data from this SA-wide project and the literature.

## **Findings**

The data 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 data affirmed that there are extensive social and emotional well being problems for Aboriginal people in Port Lincoln.

Entrenched poverty, inequity and poor access to the full range of essential human services and unemployment impact on the social and emotional wellbeing of Aboriginal people wherever they live. More employment and training opportunities and career pathways for Aboriginal people in mainstream health and community services and private enterprise are required.

The need for improved and culturally respectful service provision in local and metropolitan mainstream mental health care sectors was evident. The findings also showed that the Port Lincoln 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, particularly in crisis situations, confirming previously identified service gaps in the region. Family and carer support is crucial, highlighting the need for these special services locally. Concern about confidentiality at health and community services in Port Lincoln was expressed by several participants, and was recognised and is being actively attended to by PLAHS.

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. 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. There is also a need for advanced training for workers with specialist roles. Education at community level, to increase understanding of mental illness, drug and alcohol problems and related issues impacting on social and emotional wellbeing is urgently needed.

Access to timely and appropriate support for Aboriginal carers was highlighted as a major issue of concern. Some Aboriginal carers in Port Lincoln lacked information about their rights and the availability of allowances and resources accessed more freely by non-Aboriginal people. In particular they wanted a better understanding of legal issues around treatment orders and the role of the Guardianship Board in relation to the rights and responsibilities of carers and other family members. It was also revealed that PLAHS social and emotional wellbeing team members are overburdened and stressed due to the level of issues they are continually dealing with professionally, and constancy of their additional responsibilities to community and family in relation to mental health related problems. Innovative strategies to support them are needed.

## **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.

In response to needs identified in this research, several accredited training courses for a range of local Aboriginal and non-Aboriginal mental and general health workers, nurses, social workers, substance misuse workers, drivers and community workers were offered, including drug and alcohol and mental health comorbidity, safe medication management for Aboriginal mental health, safe management of intoxicated people, and the clean needle and syringe course. Formal evaluations of these courses indicated their popularity and that participants translated their new knowledge and confidence into improved clinical practice. This research project has strengthened collaborative links between Aboriginal and mainstream health and community services, including general practice and pharmacy, and is planning further work to better integrate service delivery, improve communication between organisations and families, and refine Aboriginal mental health and medication management coordinated care systems.

## **Recommendations**

Based on the findings, the research team, in collaboration with the Port Lincoln steering committee, developed recommendations for improving quality use of medicines for Aboriginal people with mental health problems, their carers and families, living in the Port Lincoln area. These are to:

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.
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 school children 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.
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 Eyre region 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.
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, or impaired confidentiality. This may also require high-level policy modification so that funding goes with client, rather than service.
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.
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.
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.
20. Lobby for funding specifically for respite care for Aboriginal people with mental health problems.
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 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.

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
27. Establish systems to improve access to medicines for certain clients.
28. Establish more effective systems for monitoring and supporting medication use and management.

# 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 (Appendix 2). These conversations were recorded on audiotape or in writing with informed consent of all participants (Appendix 3 and 4). 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 helps, 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

## Appendix 2. 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?

## Appendix 3. Information sheet



FLINDERS UNIVERSITY  
ADELAIDE • AUSTRALIA



ABORIGINAL  
DRUG AND ALCOHOL  
COUNCIL (SA) INC.

Professor Charlotte de Crespigny  
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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

# Appendix 4. Consent form

FLINDERS UNIVERSITY  
ADELAIDE • AUSTRALIA



ABORIGINAL  
DRUG AND ALCOHOL  
COUNCIL (SA) INC.

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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.....**