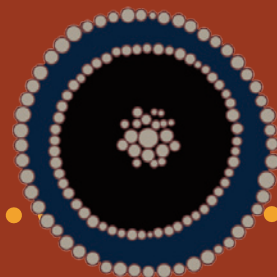
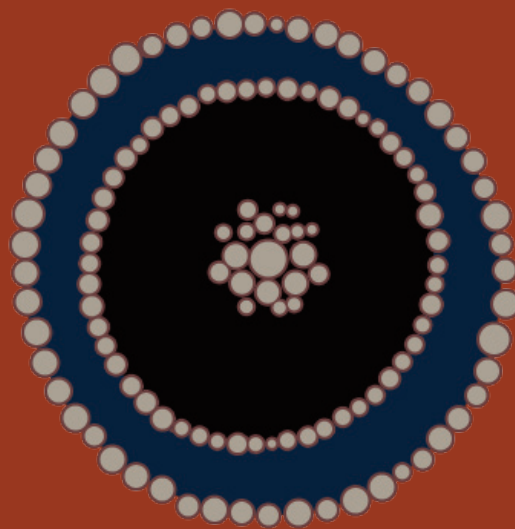
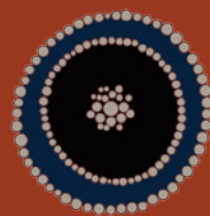


People I can call on

EXPERIENCES OF CHRONIC ILLNESS



.....
Community report

Serious and Continuing Illness Policy and Practice Study
.....

Menzies Centre for
Health Policy



People I can call on

Serious and Continuing Illness Policy and Practice Study

This community report was prepared by Tanisha Jowsey, Laurann Yen, Clive Aspin and Nathaniel Ward on behalf of the Serious and Continuing Illness Policy and Practice Study (SCIPPS). It was written with the support of Winnunga Nimmityjah Aboriginal Health Service, Aboriginal Medical Service Western Sydney, Burrenju Aboriginal Corporation, the Australian National University and the University of Sydney. Technical and formatting assistance was provided by Faiza Cheema. We wish to thank Steve Leeder, Robert Wells, Justin McNab, Penny Haora, Tim Usherwood and the SCIPPS Team for their contributions and support.

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SCIPPS is a large study based on experiences of chronic illness of people in Western Sydney and the ACT. This report talks about the experiences of Indigenous people who shared their experiences with us. Other papers from the study can be reached on www.menzieshealthpolicy.edu.au under SCIPPS publications.

SUGGESTED CITATION

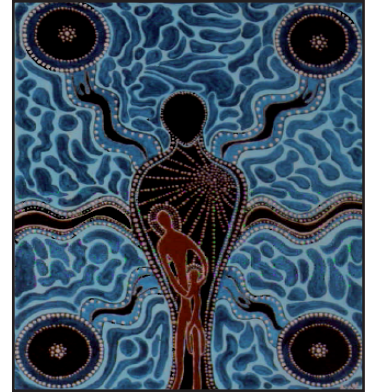
Jowsey, T., Yen, L., Aspin, C., Ward, N.J & the SCIPPS Team. "People I can call on": Aboriginal and Torres Strait Islander experiences of chronic illness. Community Report. Serious and Continuing Illness Policy and Practice Study, Menzies Centre for Health Policy 2011: Canberra.

COMMUNITY INVOLVEMENT

Aboriginal and Torres Strait Islander people were involved in this project from beginning to end as advisers, recruiters, participants and analysts. In particular, advice was provided by staff of Winnunga Nimmityjah and the Indigenous Health Interest Group of the Australian National University.

SCIPPS is deeply grateful to all those who participated in this study, especially those people living with chronic illness who shared their stories with us.

We thank Angela Scotney, Hugh Brocklebank and Tanisha Jowsey, whose art works feature in this report (for art detail see page 29).



Angela Scotney: Islands of Worimi Culture

PERMISSIONS

Consent was obtained from all participants prior to participation. The data collection and analysis were carried out by a group of six researchers with backgrounds in health and social sciences. Study approval was obtained from:

- Australian National University Human Research Ethics Committee
- ACT Health Human Research Ethics Committee
- University of Sydney Human Research Ethics Committee
- Sydney West Area Health Service Human Research Ethics Committee
- Aboriginal Health and Medical and Research Council of NSW.

Aboriginal communities operate over 150 Community Controlled Health Services (ACCHS) and Aboriginal Medical Services (AMS) across Australia, including the services involved in the SCIPPS study. “They range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services without medical practitioners, which rely on Aboriginal health workers and/or nurses to provide the bulk of primary care services, often with a preventive, health education focus. The services form a network, but each is autonomous and independent both of one another and of government. The integrated primary healthcare model adopted by ACCHs/AMSs is in keeping with the philosophy of Aboriginal community control and the holistic view of health that this entails” (National Aboriginal Community Controlled Health Organisation, 2008).

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Summary

(This is the summary of the main findings. For quotes and more detail see the full report.)

Nineteen people talked to SCIPPS researchers about what life was like living with chronic illness. They described the strengths they brought to experiences of living with chronic illness. Sharing stories and health information with friends and family is one way in which the people we talked with felt strengthened - both in practical terms and emotionally. The importance of informal support through family, friends and community cannot be underestimated.

Strengthening the capacity of people to provide effective informal support benefits everyone. People in this study also described challenges they experience in their daily lives, in relationships with family members, and in consultations with healthcare workers. We have suggested some of the ways in which healthcare workers, health services and policy can help.

People said they drew on a range of strengths to help in managing their chronic illness. These included:

- access to a repository of cultural and traditional knowledge
- insights from their own experiences which provide strategies for confronting the negative impacts of chronic illness
- drawing strength from factors such as being part of an Aboriginal community, having regular and ongoing access to primary health care, and being well-connected to a supportive family network
- the value of elders who play an important role in increasing people's awareness of the impact of chronic illness on both individuals and communities
- the value of being able to access the AMS (even if there is sometimes a long wait to see a doctor).

These strengths helped them deal with some of the challenges they faced with a chronic illness, including:

- poor access to culturally appropriate health services
- limited, or no cultural support systems in mainstream health services
- racism
- poor communication with healthcare professionals
- financial hardship
- transport difficulties
- a family history of chronic illness
- managing a number of chronic health conditions at the same time
- time consuming and poorly co-ordinated care between health services
- staying motivated to self manage.

INFORMAL SUPPORT

People we talked with attached great importance to the support that family members, peers and community provide in the management of chronic illness.

UNSOLICITED SUPPORT

People we talked with said that sometimes the support they receive from family members is not completely helpful. They said that family members sometimes nag them or growl at them. This makes them feel anxious and sometimes annoyed with their friends and family.

Similarly, some family carers told us that they do not want to nag their loved ones all the time. They said they find it frustrating when their loved ones do not listen to them and when they engage in unhealthy behaviour.

People we talked with said they want help

- People want to increase their health knowledge so they can share what they know with others.
- People only want unsolicited support if it makes them feel empowered and positive.
- Family carers want to be recognised and valued by health services for the support they provide.
- Family carers want more access to health information.

Recommendations for policy and health services

- Support programs for Aboriginal and Torres Strait Islander people with chronic illness need to help build health literacy.
- Specific family carer programs are needed to help carers know how they can help best when they are giving support.
- Health services need to recognise the role that family members play in the lives of Aboriginal and Torres Strait Islander people with chronic illness. This needs to be reflected in policies and procedures related to the care and support of people with chronic illness.

EXPERIENCING HEALTH SERVICES

People's previous experiences with health services influence their future access to health services, and some people said they avoid seeking help because of past experiences. In general, people we talked with said that the quality of health care they receive these days is much better than it was in the past but some health services and professionals still have a way to go to increase cultural safety.

People we talked with want:

- healthcare workers to communicate clearly
- healthcare workers to be friendly and accessible
- more Aboriginal and Torres Strait Islander people in the health workforce
- culturally appropriate health care
- to have sufficient time in healthcare consultations
- to be able to see their healthcare workers in the one place.

Recommendations for policy and health services

- Training more Aboriginal and Torres Strait Islander health workers.
- Recruitment and retention of Indigenous people into the health workforce is essential. Increasing success in these areas will require national, state and local action.
- Continued support for cultural awareness training for mainstream health workers and health services.
- Increased access to MBS rebates for Indigenous healthcare consultations with non-medical providers.

DEALING WITH MULTIPLE CONDITIONS

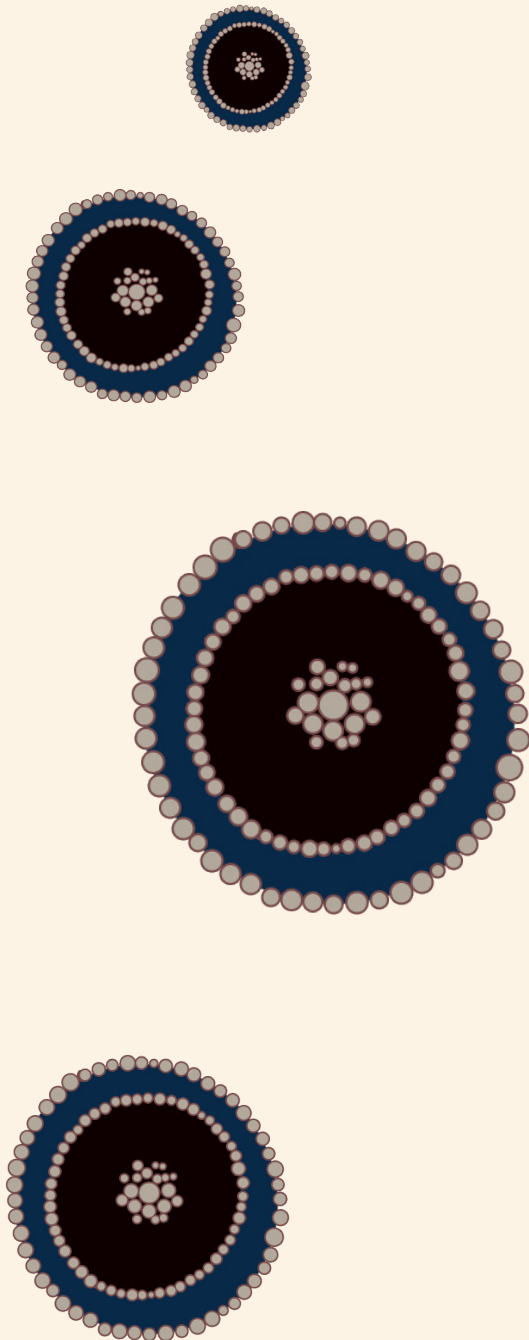
Most people we talked with had more than one long-term condition, or cared for someone with more than one condition. They said they found it difficult to know which of their conditions they needed to deal with and needed to learn a lot more because they had more than one condition. They found it hard to recognise the symptoms of each condition in the context of their other health problems. They sometimes received conflicting advice from their healthcare workers. Carers also found it difficult to manage the extra work associated with multiple conditions.

People we talked with want:

- to know how to tell the difference between the symptoms of their different conditions
- to understand better what they need to do to manage each of their conditions
- to know more about how to prevent their health from getting worse.

Recommendations for policy and health services

- Culturally appropriate health education services targeting the main issues of managing multiple illnesses, such as recognising symptoms and managing medications.
- Medication reviews when medications are changed or when there has been a change in one or more of the illnesses.



Full report

What is chronic illness?

There are many different kinds of chronic illnesses such as diabetes, asthma, arthritis, chronic renal failure, hepatitis, heart failure, cancer and epilepsy. They are illnesses that last for a long time.

The symptoms can be continuous or ongoing, such as with arthritis.

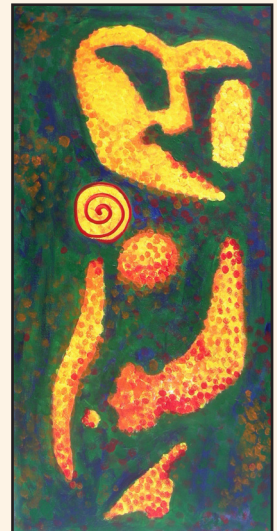
Not all chronic illnesses have continuous symptoms though. Some chronic illnesses like asthma have times when they get out of control and other times when they can be controlled pretty easily or don't require much management.

Either way, chronic illnesses last more than six months and often they cannot be cured. So once a person has a chronic illness they may have it for the rest of their life.

Each chronic illness develops in a particular way and needs to be managed in a particular way. Chronic illnesses are often managed with medications, diet and exercise.

People can have more than one chronic illness at a time and the chance of having more than one chronic illness increases with age.

The rates of chronic illness are higher among Aboriginal and Torres Strait Islander people than they are among non-indigenous Australians.



Tanisha Jowsey:
Simplify myself

What is SCIPPS?

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) is a large study looking at chronic illness. SCIPPS aims to:

- ① improve the health outcomes of people living with chronic illness
- ① reduce unnecessary hospital admissions of this group (help people stay out of hospital)
- ① develop more effective preventive strategies (help people stay healthy).

SCIPPS has engaged in different types of research. One type has been interviews with people living with chronic illness and family carers. The chronic illnesses that SCIPPS focused on were type II diabetes, chronic heart failure and chronic obstructive pulmonary disease. We interviewed people who were born in Australia as well as immigrants, people from a range of social and economic backgrounds, and people across a wide range of age groups.

Aboriginal and Torres Strait Islander people with chronic illness confront multiple challenges, which contribute to poor health outcomes. SCIPPS wanted to identify current experiences of Aboriginal and Torres Strait Islander people living with chronic illness, so we interviewed 19 people, whose stories feature in this report.



What did we ask?

Tell me about your experience in living with diabetes/COPD/CHF, OR as a carer.

What concerns you most about your diabetes/COPD/CHF, OR as a carer?

What is your understanding of diabetes/COPD/CHF?

What have been the greatest challenges that you have faced as a patient, OR as a carer?

Tell me about your experience with health professionals in terms of managing your diabetes/COPD/CHF, OR as a carer.

Tell me about your experience with health services in terms of managing your diabetes/COPD/CHF, OR as a carer.

Can you think of anything you would change in health services to improve your experiences or even to prevent negative experiences from happening (again)?

Tell me about informal support or help other than healthcare services you are getting as a patient, OR as a carer.

Have you ever had any experiences with health services where you did not feel safe?

From your experience as in Indigenous person, could you tell me what you think the main issues are for Indigenous people in dealing with the health system?

Who participated in the study?

This community report describes the experiences and stories from 19 in-depth interviews with Aboriginal and Torres Strait Islander people who had chronic illness and/or cared for a family member with chronic illness. People were recruited through two Aboriginal Medical Services (AMS) and an Aboriginal carer group.

Twelve of the people who were interviewed were men and seven were women. Their ages ranged from 34 to 70 years. Ten people were living in Sydney and nine were living in Canberra.

Three people told their stories of looking after a family member with chronic illness and 16 people told their stories of what it was like to have a chronic illness.

Seventeen people with diabetes, eleven people with chronic heart failure, and three people with chronic obstructive pulmonary disease (COPD) shared their experiences of chronic illness.

These 19 people took part in face-to-face in-depth interviews, which were audio recorded and later transcribed verbatim. They also completed a 10-minute demographic survey and provided information about their health conditions and healthcare encounters.

PARTICIPANTS' DETAILS

Characteristic	Number	Per cent
Male:Female	12:7	63:37
Torres Strait Islander	1	5
Aboriginal	18	95
Married	7	37
Age:		
<45	3	16
45-60	6	31
61-70	10	52
Chronic condition:		
Diabetes	17	89
Chronic obstructive pulmonary disease (COPD)	3	16
Chronic Heart Failure (CHF)	11	58
More than one of above	11	58
Other co-morbidities	18	95
Duration of illness (years):		
Diabetes	16.5 (SD= 16.9)	
COPD	16.5 (SD= 21.9)	
Chronic Heart Failure	16.8 (SD= 17.8)	

Experiences of informal support

People we talked with attached great importance to the support that family members, peers and community provide in the management of chronic illness.

I've got three children, and if I wanted to go away anywhere, I would say, "Who's going to be the babysitter, who's coming over?" and someone would say, "I will" and I'd drop them off there or they'd come here. So basically there were five people I could call on.

- Participant A

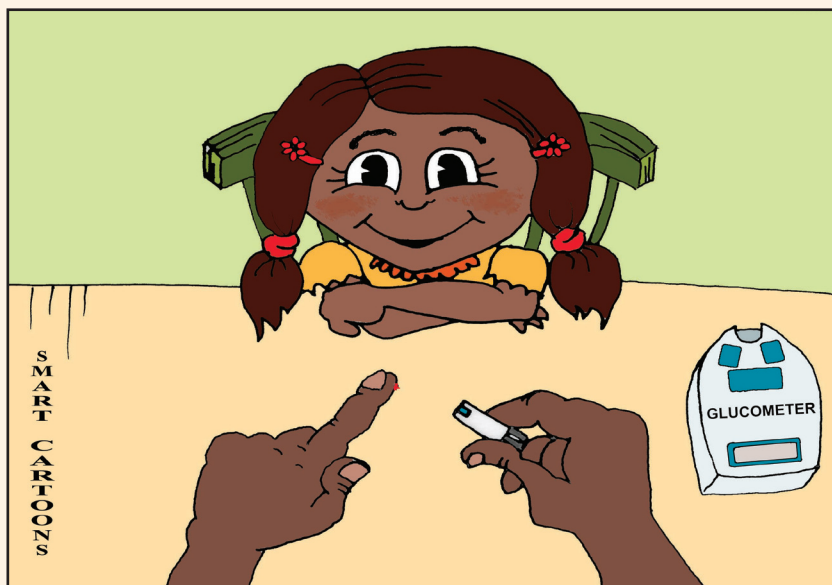
I go to these, we have a meeting, like the elders, every Friday, at the end of the month, I go to those ... Yeah, the elders, like our age, and they ... and ah the organs is diced up, like with sugar diabetes. I enjoy it, 'cause it's all gather around, you know, natter, have a good laugh and what, whatever. And yeah, it's alright.

- Participant B

People in our study said they share health information with friends and family. This information is passed down from one generation to another and between friends. Sharing health information is an important aspect of Aboriginal and Torres Strait Islander culture.

What my husband did was, when new people used to come in, after having been on [renal dialysis] for so long, when someone new comes in, he would talk to them and say, "Well this is how it all works and that" so he would talk to someone else, and they would say "Oh well, that makes it a little bit better, I can understand what's happening with me and that". And we had one really good renal ... she was like the social worker I guess, we could talk to them individually, she was lovely. She explained everything, she took you in to show you how it all worked and what was going to happen.

- Participant A



Hugh Brocklebank: Lessons in blood glucose testing

People said they share health information while they are having a yarn, often while they are waiting at the AMS to see a doctor.



Hugh Brocklebank: AMS waiting room

We share a lot . You know when we meet people we talk about things. It's like when you go in to a medical centre, you as a whiter person, you might be lucky if somebody says hello to you. If we go in and I know someone we'll have a good yarn. "How you going with yours?" "You got diabetes yeah". "How many tablets are you on?" "I'm on the needle". "Why? How high does yours get?" So there's always that yarn that we can pass on that information, "What do you do about it?" and all this stuff, and I think sharing a lot of the things that we do that's the difference because we're so small in numbers even though we've got the largest population in the country in this area I think we can walk in anywhere and we always get a "G'day" and a yarn. And not only that, if you're a bit nervous then it calms you down, a lot of us so there's a lot of aspects I suppose we think on a cultural basis.

- Participant C

People told stories about the importance of children. Young children provide optimism for the future. Adult children act as advocates and provide practical support to parents living with chronic illness.



Hugh Brocklebank, Filling the fridge, 2011

There's been times where they've given support like driving or maybe some dosh for some extra expenses or if I run out of food for the fortnight and they might help, I don't have to ask, they come and have a look and first thing you know kids do whether they're grown up or not, they open the fridge. They say, "Oh well we'll go down and get you a few of these". I say "Ooh". When you get there they say, "Well what else do you want?" I never say, this, this and this. "Come on you must need something" so. But they're quite good in that way, support today.

- Participant C

People also told us about how other family members help them manage. People who were married or had a partner said they received a lot of support and practical help from their spouse/partner.

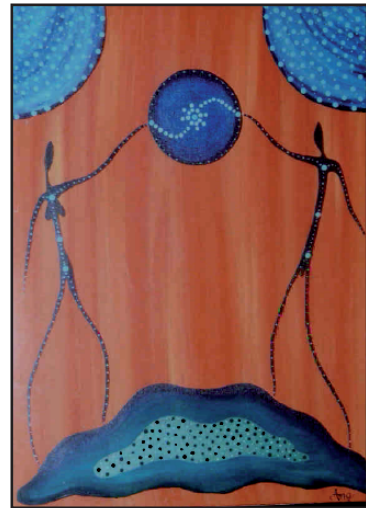
Unsolicited support

People we talked with said that sometimes the support they receive from family members is not completely helpful. They said that family members sometimes nag them or growl at them. This makes them feel anxious or ambivalent.

We understand this support as 'unsolicited support', which is the kind of support that people did not ask for and sometimes did not appreciate.

My nieces and that they all have a growl at me.

- Participant D



Angela Scotney:
Saltwater Soul Mates

Well just by nagging me, and saying to me all the time... "you shouldn't be having that Mum" or "should you be having that?" Yeah so ... Mary she's the worst one.

- Participant E

Similarly, some family carers told us that they do not want to nag their loved ones all the time. They said they find it frustrating when their loved ones do not listen to them and when they engage in unhealthy behaviour.

When he's with his own people he eats so much food because the food is very cultural. So he will not stop himself from eating and say "oh look I have to watch my sugar mate I'm diabetes, I've got diabetes". He's just going to sit there and become a part of that social network and eat and be happy, but he will suffer later for that. And there's normally a point where I'm sitting at the table glaring at him, kind of saying in a way but without verbalising it "that's enough you're going to get sick" ... I give him the look, that serious look of "that's enough". So it's quite emotionally exhausting for me when I sit there and I watch it and I know that later he's going to suffer, it's really quite tiring. And how do I ... I need to be respectful of culture and his ways but at the same time I can't afford to have a man who's sick.

- Participant F



Hugh Brocklebank: He's not listening

Experiencing health services

People's previous experiences with health services influence their future access to health services. In general, people we talked with said that the quality of health care they receive these days is much better than it was in the past but some health services and professionals still have a way to go to increase cultural safety.

I've had some really bad experiences with doctors here and I've told my [AMS] doctor about them. He [the eye specialist] was a total pig, you know ... it's just the way that they talk to you. The way ... they're belittling you. Make you feel cheap and small and "you're wasting my time here". You know? ... He was really really rude and I mean he's there to provide a service in a professional way and in a specialized area ... he made me cry ... no absolutely [I won't] go back to him.

- Participant G

People told us they found accessing health services time consuming and poorly co-ordinated.

This week, I've got three appointments, yeah. Which will be three half days, gone, you know. And you think, well, you know, that's a day and a half of my life and then next week is the same with, you know, just continuous appointments.

- Participant H

People we talked with really appreciate the quality of care they receive at Aboriginal Medical Services.

It's a great place to get together with a lot of new people, you know, a special place and you see different ones that you know and have a yarn to. ... but I've been here ever since I've been ill, and I've been away for while and I always come back, and the doctors are good. Then everybody's very good here.

- Participant J

People said poor communication with health professionals is a major obstacle to good care and support. They told stories about times when healthcare professionals provided medical advice in terms that were difficult or impossible to understand.



Hugh Brocklebank: Alien communication

When they are being addressed, they're not being spoken to in a way that they're really understanding what the illness is, how they can control it, how they can contribute to looking after their own health.

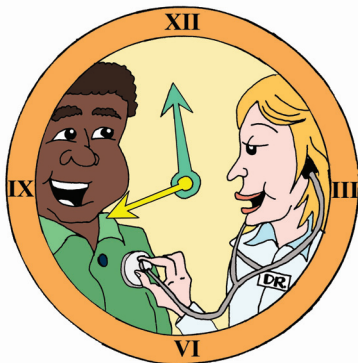
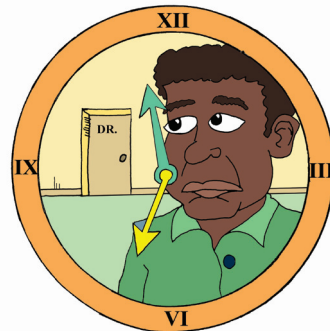
- Participant A

Other [non-AMS] medical centres, you're in you're out, there's no friendliness, there's people that well I know years ago they used to treat us differently through discrimination. You'd wait your turn particularly at hospitals, and when you take someone to hospital ... they'd make us wait six or eight hours where the others would get in and out pretty quick.

- Participant C

We get longer consultations with doctors. We sometimes get cheesed off about [waiting] but ... you get plenty of time to explain your problems. So we've got a lot of advantages.

- Participant C



Hugh Brocklebank: Doctor on the clock I & II

And that's the thing that AMSs do really well they take their time, there aren't time limits so they can actually spend a bit more time with you. But if it's an emergency case then you're going to be put in first you know that's going to happen. And there's already cultural safety in AMSs so people can go in then they're going to be comfortable to know that their needs are going to be met ...

- Participant M

If I had my way, it would be that people address [chronic illness] in words that they understand, and follow through with a full action plan, not just medication and “come back and we’ll give another blood test”. ... if you could work it in a way that it is something that’s implemented and set in place that follow through. I mean that makes people feel that you do matter.

- Participant L

Managing multiple illnesses

Almost all of the people we spoke to had more than one chronic illness and this made it more difficult for them to manage. It was difficult because they had to learn to identify the symptoms of each illness and manage each individual illness but also manage their health overall. Living with multiple illnesses was complicated when they were taking multiple medications and when they had to see multiple healthcare workers to manage each condition. Often healthcare workers were not all under the same roof, which increased the amount of time it took people to manage their health in terms of waiting times and attending consultations with healthcare workers. Family carers were often affected by these aspects of living with multi-morbidity, which meant the carer burden was increased.

But with [my husband], I think the problem started building up because of the diabetes and I guess the heart was starting to play up a little bit, but we didn’t know, and that’s what made him become more weaker. So he didn’t have the energy to do very much ... So that sort of creeps up on you, and I think that diabetes is something they say is a slow killer, and it is. Because with a lot of people, they don’t think oh the diabetes is doing a lot of damage to your organs, and can create all the other problems, so it does catch up on you.

- Participant A

It's challenging as in if the diabetes is affecting you it's a matter of knowing how it's affecting you ... when [my glucose levels] gets really really high I mean you get tired and lethargic but it's still I suppose not knowing how it really does affect you. I mean you know the lows because you just drop! You know? The highs and that are sort of a little bit hard to adjust, I suppose. I mean for me it's just - I have no idea as to how it's affecting me if they're sort of really really high. Because I don't know whether it's just - whether it's an age thing that's happening to me or whether it's menopausal you know? Because so many things are happening to your body you just don't know which is bloody which, you know?

- Participant G

If I don't get enough sleep at night [due to sleep apnoea], I'm sleeping during the day which means I'm not eating which means my sugar's coming down ... yeah it's funny, very funny [how we] vtry and balance up everything ... If I got asthma at the time or I got a cold, the machine pushes air down me throat to keep the airways open, which means that whatever's inside my chest at the time, if I've got a chest infection or something, that's you know, one's trying to come up and the other one's pushing it down.

- Participant K

Transport difficulties

There is an hourly bus service. So they give me an appointment at whatever time so we have to leave here up to two hours before the appointment because we have to go into [the town centre]. We have to get a bus from [the town centre] up to the hospital and you're probably there half an hour, three quarters of an hour early, or else it's too late for that appointment, so you will then have to wait for half an hour after the appointment too while waiting for the bus to come. So, an hour is a long interval and I appreciate the costs and the fact that the buses don't run, but from the point of view of getting somewhere without trying to drive, you know, to rely on public transport, I can't.

- Participant H

Economic hardship

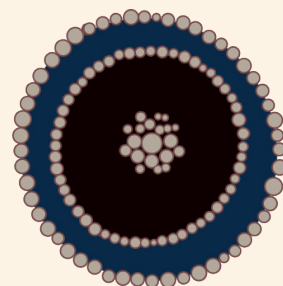
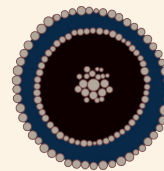
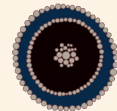
[You] go through your GP to get all the things like even the amount at Centrelink ... fill out all these forms. And sometimes Centrelink have their GPs there, but that's entirely up to them, if they don't like you know, the situation, they just knock you back ... They just said they just couldn't find the proof, like I really needed a carer at the moment ... Well it made me feel like you know, shit, 'cause I admit it myself, like you know, I needed a carer.

- Participant N

Conclusion

Nineteen Aboriginal and Torres Strait Islander people described what life was like living with chronic illness. They described strengths they brought to experiences of living with chronic illness as well as hardships encountered. Sharing stories and sharing health information with friends and family is one way in which the people in our study felt strengthened - both in practical terms and emotionally. Effective informal support through family, friends and community strengthens the capacity of people to manage chronic illness and benefits everyone. Action is needed to increase the capacity of people to provide effective support. People in this study also described challenges they experience in their daily lives; in relationships with family members, consultations with healthcare workers, in managing multiple conditions and experiencing financial hardship. We have suggested some of the ways in which healthcare workers, health services and policy can help.

SCIPPS is deeply grateful to all those who contributed to this study, especially those people living with chronic illness who shared their stories with us. We thank the healthcare providers, advisors, academics, and artists who contributed to our project.



Appendix: Recent policy context

2005 The National Chronic Disease Strategy was established by the Commonwealth Department of Health and Ageing. The Strategy provided an overarching direction for management of chronic conditions.

The Commonwealth Government announced the 2005-06 Budget, outlining the Healthy for life initiative. This initiative provided \$102.4 million over four years, aiming to improve the health of mothers and children, and better the lives of people with chronic illness.

The Australian Bureau of Statistics and Australian Institute of Health and Welfare published Health and welfare of Australia's Aboriginal and Torres Strait Islander people. It detailed the health of Indigenous people and compared it with the health of non-Indigenous people.

2006 The Australian Bureau of Statistics released the National Aboriginal and Torres Strait Islander health survey: Australia, 2004-05. This report provided a summary of health status, health actions, and lifestyle factors.

Australian Government's Department of Health and Ageing released the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government implementation plan 2003-2008, its response to the recommendations made in the National Strategic Framework.

2007 The Aboriginal and Torres Strait Islander Health Performance Framework Report 2006 was published by the Australian Health Ministers Advisory Council. The aim was to increase debate and health policy innovation as well as to inform the analysis, planning, and implementation of policy.

2008

In Canberra, Prime Minister Kevin Rudd formally apologised to members of the Stolen Generations on behalf of the government.

The Council of Australian Governments committed to six specific goals, including that of “closing the gap”, specifically looking at improving outcomes for Aboriginal and Torres Strait Islander people. These goals were supported by \$4.6 billion of funding to Indigenous-specific national partnerships in education, health, and housing.

2009

National Health and Hospitals Reform Commission released its final report: A Healthier Future for All Australians. The commission recommended streamlining the funding system for Aboriginal and Torres Strait Islander health initiatives in order to strengthen the work of community-controlled organizations.

Federal Budget 2009/10 was announced; allocating an additional \$1.3 billion for Indigenous health. The funding included: \$131 million over three years for Indigenous health services in the NT and \$13.8 million for link-up services.

Australian Government announced the establishment of the National Congress of Australia’s First Peoples, the new national representative body for Aboriginal and Torres Strait Islander people.

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Art detail

The artwork featured in this community report was kindly provided by Angela Scotney, Hugh Brocklebank and Tanisha Jowsey.

Angela Scotney is a 'Worimi' Koori woman of the Great Lakes people in NSW. Angela paints about the stories that she was told while growing up. Her style comes from being an Aboriginal woman living in a modern society who still values culture and traditions. Angela works in acrylics on canvas. Angela also works in healthcare research and health service management. In her role as a healthcare worker and health researcher Angela kindly provided advice to SCIPPS in the recruitment phase of this study.

Hugh Brocklebank of Smart Cartoons created six original cartoons to illustrate the key findings of this study. Hugh was born in Victoria, Australia and has lived in Canberra for most of his life. His cartoon work is inspired by the lighter side of life.

Tanisha Jowsey was born in New Zealand and has spent the past six years living as an artist and medical anthropologist in Canberra. Tanisha is the senior research officer on SCIPPS. Tanisha's two paintings that feature in this report were painted during her time with SCIPPS.

LIST OF WORKS

Angela Scotney, Islands of Worimi Culture, acrylic on canvas, 2006*

Angela Scotney, Saltwater Soul Mates, acrylic on canvas, 2006

*Angela Scotney's art work is the inspiration for the title page, designed by Tanisha Jowsey and executed by Kimberley Brady.

Hugh Brocklebank, Alien communication, 2011

Hugh Brocklebank, Doctor on the clock I, 2011

Hugh Brocklebank, Doctor on the clock II, 2011

Hugh Brocklebank, AMS waiting room, 2011

Hugh Brocklebank, Lessons in blood glucose testing, 2011

Hugh Brocklebank, He's not listening, 2011

Hugh Brocklebank, Filling the fridge, 2011

Tanisha Jowsey, Simplify myself, acrylic on stretched canvas (60 x 120cm), 2008

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Jowsey T, Yen L, Wells R. National Health and Hospital Reform Commission Final Report and patient-centred suggestions for reform. *Australian New Zealand Journal of Public Health*. 2011 [in press]

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Notes