Improving the wellbeing of Melbourne-based Aboriginal people with chronic disease and experiencing depression, anxiety or a related mental health disorder: A Wurundjeri community driven initiative

Study Findings and Recommendations

Report to

beyondblue Victorian Centre of Excellence

Prepared by

Dr Rosemary Higgins, Dr Barbara Murphy & Ms Karmen Jobling
on behalf of the Project Team

28th June 2013
**Project title**

Improving the wellbeing of Melbourne-based Aboriginal people with chronic disease and experiencing depression, anxiety or a related mental health disorder: A Wurundjeri community driven initiative.

**Community title**

Bundap Marram Durn-Durn ‘Good - Mind -Body’

**Project team**

Dr Barbara Murphy\(^1,2\) (Chief Investigator) Dr Rosemary Higgins\(^1,3\), Ms Karmen Jobling\(^1\), Aunty Diane Kerr\(^4\), Dr Phyllis Lau\(^5\), Dr Marian Worcester\(^1,2\)

1 Heart Research Centre, Melbourne
2 Department of Psychiatry, The University of Melbourne
3 Department of Physiotherapy, The University of Melbourne
4 Wurundjeri Tribe Land Compensation Cultural Heritage Council Incorporated
5 General Practice and Primary Health Care Academic Centre, The University of Melbourne
Acknowledgements

The Bundap Marram Durn Durn team would like to acknowledge the Traditional Custodians of the land on which this project was conducted and subsequent report produced. The team would also like to thank all the service providers and community members who gave generously of their time to contribute stories towards this project.
# Table of Contents

Table of Contents ........................................................................................................................................... 5

Executive Summary ...................................................................................................................................... 12

Background ................................................................................................................................................... 14

Aims .............................................................................................................................................................. 15

Methods: Bundap Marram Durn Durn ......................................................................................................... 17

Project Governance: Bundap Marram Durn Durn .................................................................................... 17

Project Reference Group ...................................................................................................................... 17

Ethics ..................................................................................................................................................... 17

Wurundjeri TLCCHC Committee of Management (CoM) & Dialogue with Wurundjeri Elders ............ 17

Steering Committee: Bundap Marram Durn Durn ............................................................................... 18

Research Team ..................................................................................................................................... 18

Focus of the report ................................................................................................................................... 19

Method Study 1: Service Providers Consultation ......................................................................................... 20

Sample ...................................................................................................................................................... 20

Sample size ........................................................................................................................................... 20

Procedure study 1: Service Providers Consultation ................................................................................. 20

Participant recruitment ........................................................................................................................ 20

Data analysis and interpretation .......................................................................................................... 21

Results Study 1: Service Providers Consultation .......................................................................................... 22

Study sample: Service providers ............................................................................................................... 22

Themes Arising: Service Provider Consultation ......................................................................................... 22

Depression, Anxiety and Chronic Illness ................................................................................................... 23

Depression and anxiety prevalence ........................................................................................................ 23

Chronic disease and depression or anxiety .......................................................................................... 24

Communicating about depression or anxiety ...................................................................................... 24

Stigma ............................................................................................................................................... 24


Data analysis and interpretation .............................................................................................................. 53

Results: Study 2 Client Consultation ............................................................................................................. 55

Study sample ............................................................................................................................................ 55

Themes arising: Client Consultation ............................................................................................................. 55

Chronic disease and depression or anxiety .............................................................................................. 55

Family members with mental health issues .............................................................................................. 56

Suicidality .............................................................................................................................................. 57

Managing depression and anxiety ........................................................................................................ 57

Causes of depression ............................................................................................................................ 58

Being the strong one ........................................................................................................................ 59

Caring responsibilities ....................................................................................................................... 60

Relationships .................................................................................................................................... 61

Grief and loss .................................................................................................................................... 62

Needs Identified: Synthesis of Study 1 & 2: ................................................................................................. 63

Service Provider and Client Consultations ................................................................................................ 63

1 Need for cultural connections .......................................................................................................... 64

2 Need for community......................................................................................................................... 64

3 Need for pride ................................................................................................................................... 65

4 Need for information........................................................................................................................ 67

i) Services and entitlements information ........................................................................................ 67

ii) Mental health information ........................................................................................................... 68

iii) Family history information ........................................................................................................... 69

5 Need for someone to care (case management and support) .......................................................... 69

6 Need for Healing ............................................................................................................................... 71

i) Cultural Healing ........................................................................................................................ 71

ii) Counselling ................................................................................................................................... 72

iii) Story telling ................................................................................................................................... 72

iv) Support Groups and Yarning Circles ............................................................................................. 73
What helps?

‘What Helps?’: Service providers’ perspective

Building community
Connecting with culture
Information about mental health
Reducing stigma and shame: Normalisation
Telling my story
Building pride
Holistic focus
Support groups
Belonging
Yarning
Counselling
Intense support

‘What helps?’: Clients’ Perspective

Connecting with community
Connecting with culture
Information on services/supports
Telling my story
Access to trusted medical care
Someone who cares and follows up
Access to community services
Counselling

Possible initiatives to address the identified needs of the community

How these initiatives arose.

Table 1  Things that help and possible initiatives to address these.
Meeting the needs: Diagrammatic Perspective ................................................................. 103

WURUNDJERI COMMUNITY WEBSITE .............................................................................. 104

Purpose: .................................................................................................................................. 104

Project Aims .............................................................................................................................. 104

Target group .............................................................................................................................. 104

Key needs addressed ................................................................................................................. 104

Key strategies.............................................................................................................................. 105

Evaluation ................................................................................................................................. 105

WURUNDJERI WELLBEING CENTRE ....................................................................................... 106

Purpose: .................................................................................................................................. 106

Project Aims .............................................................................................................................. 106

Target group .............................................................................................................................. 106

Key needs addressed ................................................................................................................. 106

Key strategies.............................................................................................................................. 107

Evaluation ................................................................................................................................. 107

CARE COORDINATION PILOT PROJECT ............................................................................... 108

Purpose: .................................................................................................................................. 108

Aims ......................................................................................................................................... 108

Target group for pilot ............................................................................................................... 108

Key needs addressed ................................................................................................................. 108

Key strategies.............................................................................................................................. 109

Evaluation ................................................................................................................................. 109

DIGITAL STORIES (NARRATIVE HISTORY) PROJECT ............................................................ 110

Purpose ................................................................................................................................... 110

Aims ......................................................................................................................................... 110

Target group .............................................................................................................................. 110

Key needs addressed ................................................................................................................. 110
Executive Summary

The current project was proposed as a partnership between the Wurundjeri Tribe Land Compensation Cultural Heritage Council Incorporated (TLCCHC), the Heart Research Centre (HRC) and The University of Melbourne’s General Practice and Primary Heart Care Academic Centre in October 2010. The overarching aim of the project was to identify and address the needs of Melbourne-based Aboriginal people with chronic illness and experiencing depression, anxiety or a related disorder. The project was proposed as a Wurundjeri community-driven initiative. In November 2010, the project received funding from the beyondblue Victorian Centre of Excellence. The project officially commenced in December 2010.

The project was headed by a Project Team comprising researchers and project workers from each of the three partner organisations. The project was overseen by a Project Steering Committee comprising key personnel from each of the three partner organisations. At one of the early meetings of the Steering Committee, the project was renamed Bundap Marram Durn-Durn, meaning “good” “mind” “body” in Woiwurrung language. A Project Reference Group, comprising representation from key stakeholders and community organisations, was established to provide input into the project.

The project was proposed to be undertaken in two distinct phases. The first phase involved consultation with Aboriginal people with chronic illness and experiencing depression, anxiety or a related disorder (the client group), and with service providers who assisted the client group. The second phase involved the identification, implementation and evaluation of initiatives to address the identified needs of the client group. This report provides an overview of both phases of the project.

Phase 1 of the project identified many key needs of the client group, from both the service provider and client perspective. These needs highlight the depth and breadth of the loss, pain and trauma of Melbourne-based Aboriginal people. This report expands on these themes with particular attention to the interplay between chronic disease and mental health, particularly anxiety and depression.

Phase 2 of the project identified several ‘possible initiatives’ to address the needs of the client group. These initiatives were proposed by the Project team in consultation with both the
Steering Committee and other key members of the Wurundjeri community. This report outlines each of the possible initiatives and details the progress to date in the development and evaluation of each of these initiatives.

The first order initiatives were proposed to address the over-arching needs of the community – the needs for connection, healing and information. The two key initiatives at this broad level are:

i) the development of a website for the Wurundjeri Community

ii) the establishment of a Wellbeing Centre for the Wurundjeri Community

The second order initiatives were proposed to address the more specific needs of the community – namely the needs for story telling opportunities, building pride within the community, information about services, access to trusted medical care and navigation through the service system, and the need for the traditional Wurundjeri owners to welcome others onto their land. The four key initiatives at this lower level are:

iii) Case management support

iv) Digital story-telling

v) Community Services Card

vi) Welcome to Country Pack

Each of the proposed initiatives is at a different stage in its development and implementation. Given the complexity of the needs of the community, the breadth of the proposed initiatives and the costs of implementation and evaluation, it will be some time before the initiatives are fully realised and evaluated. Development and implementation of the proposed initiatives is a huge undertaking which will inevitably continue well beyond the life of the current project.
Background

Chronic disease and mental health disorders are the greatest contributors to the life expectancy gap between Aboriginal and non-Aboriginal people (1). Research indicates that Aboriginal people experience a disproportionate burden of chronic disease including cardiovascular, kidney and respiratory disease, depression and diabetes (2). In 2004, three times as many Aboriginal people reported experiencing diabetes or high sugar levels compared to non-Aboriginal people (3). Compared with non-Aboriginal people, Aboriginal people are 3 times more likely to die from cardiovascular disease (CVD) and their incidence rate of treatment for end stage renal disease is 8 times higher (4,5,6). Mental health disorders at 15% are identified as one of the leading causes of the burden of disease for Aboriginal people (1, 7).

The interrelationships and incidence of comorbidities of chronic diseases further increases the risk of early death and disability in this vulnerable population group (3,4,5,6). Depression, anxiety and other related mental health disorders are often exacerbated by the diagnosis and progression of chronic disease (8). This relationship is particularly strong in people with pre-existing mental health issues. In addition, depression is identified as a risk factor for chronic disease (9).

The limited investigations in the area of Aboriginal chronic disease and mental health have mainly occurred with remote communities. Indeed, our literature search identified a complete absence of qualitative studies in the field of chronic disease and mental health within the urban Aboriginal community context. The Wurundjeri community, the Traditional Custodians of Greater Melbourne, as represented by the Wurundjeri Tribe Land Compensation Cultural Heritage Council Inc. (TLCCCHC), were concerned about the large number of people within the urban community with chronic disease who were also experiencing depression and/or anxiety. While the community sought interventions to improve social emotional wellbeing outcomes, they also wanted to ensure that any initiates would be appropriate for the context within which their members experienced their particular challenges. To deliver an appropriate initiative, the community recognised that they required further information about the patient journey as well as workforce capacity.

The National and State implementation plans and policies for ‘Closing the Gap in Indigenous Health Outcomes’ have reflected multisectorial agreements underlining the need for all to work
together to increase access to culturally competent services that meet the needs of Aboriginal people (10). The priority areas of “primary health care services that can deliver” and “fixing the gaps and improving patient journey” focus on building the capacity of service delivery (10). In addition to this, the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) recommends the following mechanisms to build the capacity of social determinant research within Victorian communities:

- Education and training (for service provision, workforce development, career progression and staff retention),
- Health services to be embedded within the community and to operate in an environment of community development
- Health and research priorities to be identified within the community
- Partnerships are integral for funding, resourcing and for concrete improvements in health (11).

These recommendations, along with the principals for translating research, policies and report findings into practice with Aboriginal people as outlined by the National Health and Medical Research Council (12), guided the development and implementation of this project.

Given the paucity of qualitative research with respect to the urban-Aboriginal communities experience of chronic disease in the context of depression, anxiety and/or related disorders, the present study was designed to explore the experiences and needs, as well as appropriate community driven initiatives, for this vulnerable consumer group as identified via qualitative methods.

**Aims**

The overarching aim of the present study was to facilitate community driven initiatives to improve the wellbeing of Melbourne-based Aboriginal people with chronic disease who are experiencing depression, anxiety and/or related disorders. The study was principally designed to be qualitative in design.
In addition to this overarching aim, the specific aims were:

- To investigate the perceptions and training needs of Aboriginal service providers who work with Melbourne-based Aboriginal people with chronic disease who are experiencing depression, anxiety and/or related disorders, henceforth referred to as the ‘client group’ (Phase 1).
- To investigate the experiences and needs of the client group ‘client group’. (Phase 1)
- To develop, implement and evaluate appropriate initiatives for the client group as well as determine whether the initiative meets the identified community needs (Phase 2).

More specifically, with respect to service providers, the following aspects were investigated:
- Service Providers knowledge of a) the client group’s patterns of service use; b) depression; c) anxiety; d) resources that are particularly helpful for the client group; e) the relationship between chronic disease as well as depression, anxiety and/or related disorders amongst the client group; f) barriers and enablers for the client group in accessing services; f) current gaps in the care of this particular client group, and lastly g) possible solutions to identified problems.

More specifically, with respect to the client group, the following aspects were investigated:
- a) the onset and experience of chronic disease; b) the types of services used to manage health; c) barriers and enablers in accessing service to manage health d) experiences of depression; e) experiences of anxiety; f) gaps in services; and g) reflections on types and services and/or programs that could generally enhance wellbeing.
Methods: Bundap Marram Durn Durn

Project Governance: Bundap Marram Durn Durn

Project Reference Group

The project was overseen by a Project Reference Group which convened twice during the life of the project (February 2011 and February 2012). The Project Reference Group comprised representation from the following organisations: the Wurundjeri TLCCHC, Elders of the Wurundjeri community, the Heart Research Centre (HRC), Onemda VicHealth Koori Health Unit, the Royal Women’s Hospital, The Royal Melbourne Hospital, Department of Health, The University of Melbourne General Practice and Primary Health Care Academic Centre, the Victorian Aboriginal Health Service (VAHS), Victorian Aboriginal Community Controlled Health Organisation (VACCHO), Bunurong Health Service, Eastern Access Community Health (EACH), Mullum Mullum Indigenous Gathering Place, Western Suburbs Indigenous Gathering Place and Southern Health.

During the second Project Reference Group, the Project Manager presented the preliminary project findings (Service Provider interviews) in an interactive presentation format. Attending members were asked to identify additional barriers to service utilisation for the client group and to facilitate access to established community groups for the client group interviews. Feedback from the second Project Reference group has been incorporated where appropriate in this report.

Ethics

Ethics approval for the project was sought and granted from The University of Melbourne Human Research Ethics Committee.

Wurundjeri TLCCHC Committee of Management (CoM) & Dialogue with Wurundjeri Elders

The Research Team provided several brief written reports for presentation and review at the Wurundjeri TLCCHC Committee of Management (CoM) meetings during the preceding 12 months of the project. The Research Team as represented by Dr Rosemary Higgins also presented the preliminary findings from Study 1 (Service Providers) and Study 2 (urban
Aboriginal consumers) to the Wurundjeri TLCCCHC CoM for feedback in November 2012. The Wurundjeri TLCCCHC CoM members were asked to identify which of the themes emerging from the project resonated most with their knowledge of their community. The CoM members were also which approach or approaches identified from the findings where preferred as interventions with respect to addressing the challenges experience by the community. Further to this, the Research Team consulted with Elders from each of the three family groups (Nevins, Terrick and Wandin) not represented on either the CoM, the project Steering Committee or the Research Team with respect to possible project interventions. The consultation was undertaken in order to ensure that the views of as many community members as possible were included to inform the development of the intervention aspect of the project.

**Steering Committee: Bundap Marram Durn Durn**
The month-to-month project proceedings were overseen by a Steering Committee, which over the course of the project comprised representation from each of the three Wurundjeri Tribe family groups as well as successive incumbent Wurundjeri TLCCCHC CEO’s, staff from the Heart Research Centre (HRC) and the General Practice and Primary Health Care Academic Centre, The University of Melbourne. At the time of writing this report sitting committee members comprised Dr Barbara Murphy, Dr Rosemary Higgins, Ms Karmen Jobling, Aunty Diane Kerr, Aunty Alice Kolasa, Stephen Fiyalko, Carolyn Woolmore, Dr Phyllis Lau and Dr Marian Worcester. Former Steering Committee members have included Ms Meg Goulding, Aunty Irene Morris, Ms Jacqueline Morris, Ms Stacie Piper, Ms Glenda Mongta, Ms Barbara Johnson and Ms Lynell Angus.

**Research Team**
At the time of writing this report, the Research Team comprised Dr Barbara Murphy (Chief Investigator, Director of Research HRC), Dr Rosemary Higgins (Senior Research Fellow, HRC), Ms Karmen Jobling (Project Manager & Research Fellow, HRC), Aunty Diane Kerr (Wurundjeri Elder/ Wurundjeri TLCCCHC Wellbeing Project Officer), Dr Phyllis Lau (Lecturer, The University of Melbourne) and Dr Marian Worcester (Director, HRC). Former Research Team members have included Ms Barbara Johnson (Research Assistant, Heart Research Centre) and Ms Lynell Angus (Project Officer / Research Fellow, HRC).
Focus of the report

This report will focus directly on the issues of depression, anxiety and chronic illness, what helps and community needs.
Method Study 1: Service Providers Consultation

Sample
Eligible participants were Service Providers who service Melbourne urban-Aboriginal community members with chronic disease and experiencing depression, anxiety and/or related disorders.

Sample size
Based on initial discussion amongst the founding Steering Committee members, it was anticipated that conducting a maximum of 15 in-depth interviews with services providers would be possible during first phase of the project. Due to community politics and interest in the topic, demand from service providers to be interviewed by the project exceeded expectations. The Reference Group and Steering Committee believed that the project team needed to complete these additional interviews to harvest the opinions of a diverse group of services providers representing both mainstream and Aboriginal organisations. Interviews were conducted with 26 service providers rather than the 15 initially specified.

Procedure study 1: Service Providers Consultation

Participant recruitment
The identification of eligible participants involved; (1) the founding Steering Committee members compiling a list of known relevant Service Providers; (2) a review and subsequent expansion of the initial list of potential participants following the reformation of the Steering Committee membership in early 2011 and (3) key services and providers being identified in situ interviews. Following the identification of appropriate services and service providers, contact was then made in the following ways: in person, via telephone and e-mail (and various combinations thereof). Either one or two members of the Bundap Marram Durn-Durn project interviewing team, typically either Ms Karmen Jobling and/or Aunty Diane Kerr, travelled to a location specified by the participating Service Provider at a time that was identified as convenient by the participant. The duration of the interview ranged from 45 to 120 minutes, with most interviews being an average of 90 minutes in duration. Project Information Sheet (Appendix I), Consent Form (Appendix II) and Interview Schedule for service providers (Appendix III) are appended.
Data analysis and interpretation

After transcription, the interviews were analysed by Dr Higgins And Dr Murphy using procedures recommended by Patton (13) for themes relating to service providers’ knowledge of a) the client group’s patterns of service use; b) depression; c) anxiety; d) resources that are particularly helpful for the client group; e) the relationship between chronic disease as well as depression, anxiety and/or related disorders amongst the client group; f) barriers and enablers for the client group in accessing services; f) current gaps in the care of this particular client group, and lastly g) possible solutions to identified problems. An inductive approach to content analysis was used to allow the themes to emerge from the quotes (13). Interview tapes were listened to and transcripts read repeatedly to ensure accuracy and to include relevant information from field notes (e.g., pauses, laughter, overall mood of participants). The basic unit of analysis was defined as quotes from the transcription that represented participants’ experiences of their work with the client group as it related to the categories a – g as identified above. Quotes were clustered with other quotes with similar meaning, forming raw data themes (13). Raw data themes were inspected for overlap and commonalities and, where appropriate, merged together to form higher-level themes. Higher level themes were labelled ‘first-order themes’ or ‘second-order themes’ accordingly with the highest level themes labelled ‘general dimensions’. General dimensions represented the highest-level, where no more themes could be uncovered.

Key quotes are included in the report to illustrate each of the key themes. Interpretation of the data was conducted under the supervision of the Associate Investigator Aunty Diane Kerr, to ensure the cultural appropriateness of data interpretation.

The results presented here draw on the qualitative data analysis undertaken to date. Further qualitative findings will be available over the next 12 months.
Results Study 1: Service Providers Consultation

Study sample: Service providers

Participants comprised 26 urban-Aboriginal service providers. Twenty-two female and 4 male participants were interviewed. Participants were sourced from both Aboriginal specific and non-Aboriginal specific services including hospitals and community centres. Participant’s employment roles were varied and included: Managers, Health Promotion Officers, Project Officers, Aboriginal Health Promotion and Chronic Care Workers (AHPACC), Home and Community Care Workers (HACC), Aboriginal Health Liaison Officers (AHLO), Aboriginal Liaison Officer (ALO), Outreach Workers, Nurses, Psychologists, Planned Activity Co-ordinators (PAC) and Elders. Some participants held dual positions.

Themes Arising: Service Provider Consultation

A range of broad themes arose from the interview data. These included the following broad key thematic areas:

- Depression
- Anxiety
- Complexity of needs
- Cultural safety
- Drug and alcohol issues
- Needs and role of Elders
- Healing and coping
- Grief and loss
- Trauma
- Identity and pride
- Stolen Generation
- Impact of the past
- Lateral violence
- Mental health and chronic illness
- Role of the health worker


- Service utilisation
- Shame
- Social support
- Personal stories of coping with depression, anxiety and chronic illness

**Depression, Anxiety and Chronic Illness**

**Depression and anxiety prevalence**

A very high prevalence of depression and anxiety was noted by most participants “So, like, depression, I think a lot of our community suffers from depression. A lot, look, I might be over-exaggerating, but I’d say half (have depression)—which is terrible to say.”

“I reckon it’s probably safe to assume that everyone’s coming in with some sort of form of depression or anxiety.”

“It’s (depression) one of the most common presenting issues that we deal with here anxiety is too, I think that’s on the increase”

“It’s so common for people to be really anxious.”

**Being Aboriginal and having depression were inextricably linked according to one interviewee:**

“If you’re an Aboriginal you will have it (depression) all the time, no matter (if) you’re in a CEO position or whether you’re in grassroots, it sits on your shoulder continually”
Chronic disease and depression or anxiety

In terms of depression in community members with a chronic disease, the prevalence of depression was seen as even higher: “I’d be confident to say three quarters of the Aboriginal community (have depression)”; “with a chronic disease, (you) do, do suffer with depression.” Interviewees commented on the extremely high prevalence of mental health problems, (not all of which are diagnosed) in Aboriginal consumers with a chronic illness: “If it’s not chronic disease and depression, it seems to be chronic disease and anxiety.” While a couple estimated “around half” of clients with a chronic disease had depression or anxiety, most estimates ranged between “three quarters” (75%) and “99.9%”, “I would say eight out of ten (Aboriginal consumers) that walks through my door has a (diagnosed) mental health issue.”; “you could say every person (seen) in that system has got a mental health issue...some are treated and some aren’t....So there’s half the people that are diagnosed (and) there’s the other half that aren’t diagnosed.”

“99.9 per cent of clients that I’m working with that have chronic issues have mental health issues. Whether it’s anxiety, depression, whatever, I really, honestly can’t say any of the clients that I have ever dealt with haven’t had other serious mental health issues. Every single one has, whether it’s depression, anxiety... When I’ve been dealing with them with their chronic illnesses, I’ve picked up that they’ve had the anxiety, or I’ve picked up that they’ve had depression.”

Communicating about depression or anxiety

Stigma

Interviewees described a reluctance in the community to talk about depression or anxiety. This reluctance leads to someone with mental health problems “really off their tree” or “right off troppo” being described as having “bad nerves”. This was readily explained as “stigma and shame”; “cause people don’t really like talking about it ”; “cause it’s got that sort of stigma about it, It’s a shame factor”.
“Mental illness is not a bad thing. It’s just what happens for some people. ... They (community) just think anything to do with mental, they’re f***ed in the head, more or less, like they’re not there.”

Social and emotional wellbeing

Interviewees were very clear that when working with community it was more useful and appropriate to talk about “social and emotional well-being” or “emotional and spiritual well-being” rather than mental health, depression or anxiety. Emotional wellbeing was described as “just how they view their journey”. Reluctance to use mental health terms was very apparent: “I don’t like using the term ‘mental health’, better-suited as ‘wellbeing’ for our people”; “nobody wants to talk about being depressed.” This difficulty with mental health terms was explained as “when you talk to Kooris about ‘mental health’ they think of psych wards, psychiatrists and tablets and all that sort of stuff.”

“I don’t say you’ve got mental health issues or there’s something wrong with your head, usually, I talk to them about the social and emotion spirit. I would use terms, ‘how do you feel like, how does your soul feel today? Are you sad on the inside?’ That sort of terms and I found that a lot of patients respond well to that”

“I always go with you know sadness of the soul or like your spirits you know you got spirit sadness, that sort of thing. And sometimes I just ask them if they’ve got sorry business that they’re worried about and they want to talk about so, and you find that they’re very open to that.”

“I s’pose I use (the term) ‘grief and loss’ a lot more, I say to them ‘you seem to be really, really sad. You seem like you have a lot of grief and loss’”

Interviewees outlined the importance of using simple language when talking about depression with community members “I don’t like using big words. I like to keep my language simple”
“You’ve just gotta talk their language; listen to how they say stuff and say ‘well, you know, this is because you’re feeling that way.’ It’s about the feelings.”

Another expressed the need for **non-direct, circular communication** when talking to people in the community about mental health issues such as depression,

“I try and use things that I’m not going to be sort of relating straight to that person on that basis because I don’t think pointing it out to the person there and then, ‘bang, bang, bang, this is what it is’, is really going to get it through.”

A number of interviewees expressed complete **distaste for ‘jargon’** emphasising the importance of listening and casual relaxed communication when discussing issues of depression:

“I told these whitefellas, you know ‘talk to us. Don’t use that jargon stuff, you know, because they won’t take any notice. You come and talk with us ... Just like a friend. Be a friend first’”

“I think you kind of have to take the medical terms out of what is and just use your more friendlier terms because you don’t want to tell someone who’s got mental health issues that they’re crazy. So you go, ‘got too many worries?’”

**Use of metaphors**

Metaphors were often used as a way to assist community members to understand depression and other mental health issues. These were also seen as a way to reduce the stigma and shame surrounding depression and other mental health issues: “I’d show them visually. I’d call it down in the dumps. I wouldn’t actually say you’ve got depression unless a doctor’s come and sit there and there’s meds on one side because it can be very baulking”.

---

26
Mechanical metaphors were used by some, with depression described as feeling like “you’re walking in mud at the moment and you just can’t get out of the mud and you feel like you’re sinking” or occurring because of “pressure built up on them” or resulting in a breakage “so the whole, or holistically, you’re looking at a person that’s really broken”. Another interviewee used environmental metaphors to explain both depression and anxiety to Aboriginal consumers:

“I say look, you’ve got a beautiful, big tree here. You’ve got lots of roots everywhere and these roots are really healthy to begin with because they’re out there in the soil and everything’s happening and then all of a sudden a bit of a dry season comes along. Things aren’t quite right. Things are getting harder. And the roots aren’t really tapping into what they need anymore. And what starts happening to that tree is, it starts to droop.’ And then I say ‘it droops even more’. So when you’re feeling depressed, often you’re a bit like that saggy tree.’ you’re not getting what you need. You don’t know how to get it back again. You’re not getting the rain; you’re not getting the nutrients. You’re not getting everything that you need in your life to be able to say ‘hey, I’m ok again and I can cope with this’”

“I use the shiver grass. (to explain anxiety), there’s a little grass that shivers, ok. It feels everything in the earth and it grows down near the beach. It’s actually introduced to Australia; it’s actually South African, but it’s always shivering and anxiety makes you feel that inside. So I say, you know, ‘it’s like the shiver grass. It’s just how you’re feeling inside and you’re getting … and you know, even when you’re still, you feeling like you’re still in here and things aren’t quite right and you’re feeling exhausted and tired or you’re overworking and you’re doing all this sort of stuff and it’s all part of the shiver shake business.’”
Awareness of symptoms of depression

Depressed mood

Having a ‘depressed mood most of the day’ one of the main depression diagnostic criteria was recognised by nearly all interviewees as an important symptom of depression. Interviewees commonly used the term ‘sadness’ with depression described as “being in a sad mood or a low mood” or feeling “just sad and down all the time”; “just sadness” or “feeling down” or being led into “darker spots”. According to one interviewee “Depression is when someone feels sad. That’s the bottom line. ...They’d look sad or they’d say something that would say that they were sad”. Many interviewees were readily aware of the depressive symptom of prolonged low mood.

Interviewees identified depression as a mood state “being in a sad mood or a low mood” or “feeling down, too down” or more simply “it’s when you’re sad about something”. Depression was commonly described as “sadness”, “just the sadness” or being “in that sad state”. A couple of participants added a time frame to the symptomatology referring to the sad mood being omnipresent, “they chronically feel down” with sadness being present “always” or “all the time”. Crying was named as a way of identifying the sadness “they cry all the time”.

‘Lack of interest or pleasure in usual activities’, a main depression diagnostic criteria was not clearly recognised as a symptom of depression. Rather, participants described a state of “isolation” or social withdrawal. People with “not wanting to go out of the house”; “having no social interaction”; “they just don’t want to go out”; “people withdraw and stay at home”. A couple of participants highlighted that this withdrawal was from those closest with “a lack of interest in participating in family or community activities” or “not linking in with the community, not seeing their kids” noted as problematic symptoms. Beyond isolation, a few interviewees recognised a ‘lack of interest or pleasure in usual activities’ where people were seen as “not wanting to do anything” or “not doing what they would normally do” but also that this wasn’t a choice “they can’t do things”

Somatic symptoms of depression

Somatic symptoms of depression were less readily described. No interviewee mentioned dramatic changes in body weight as a possible symptom of depression, a few described the symptom of reduced appetite “they just don’t want to eat” and only one referred to change at
both ends of the appetite spectrum “they might not be eating or(be) over-eating”. Likewise, only three participants mentioned issues with sleeping behaviour as symptomatic of depression, with only two describing insomnia “not sleeping” and a single interviewee referring to either insomnia or hypersomnia “they could sleep a lot, (either) not sleeping well or sleeping too much.”

Participants appeared to be somewhat aware of psychomotor agitation or retardation and fatigue or loss of energy as symptomatic of depression but these appeared to overlap to some extent. This was commonly described as a state of “no motivation”. A couple of participants noted that this reduced individuals’ capacity for self-care “(people with depression are) struggling getting out of bed; that is struggling to do normal house duties, to clean or to cook or to go down the street, or to get out of their dressing gown. They just don’t want to get out of bed.”; “(they are) not even want to get up and do anything whether it’s make their bed or have a shower”. Depression was seen to affect the very fabric of family life “it interferes in their sexual behaviours (and) in how they function as parents.” One interviewee described depression as “a severe impediment to your functioning in the system of the world today”.

A few participants described a state of “lethargy” or “just wanting to sit there and do nothing”. “Not wanting to get out of bed”, “struggling to get out of bed” or “not being able to get out of bed” were commonly described as indicators of depression “it’s just something you can’t get yourself out of”. A number of interviews recognised “being tired all the time” or “exhausted” as symptomatic of depression.

“There’s depression where the person can become so mentally and physically exhausted that they can’t motivate themselves or get up.

Or they’re just, just so fed up with life. Basically, they’re just fed up with life and they’re just weak, exhausted. Just had enough.”

“(depression is) more the feeling of them feeling down all the time and not having the power to sorta rise above it a bit.”
Cognitive symptoms of depression

Cognitive symptoms were named by a small number of participants. Four interviewees recognised a diminished ability to think or concentrate as symptomatic of depression. This was variously described as “the brain not functioning the way it should be” or “when a person does not function in their thought patterns as they usually are” or as an “interference in the way they’re thinking about the world at the time”. The fourth interviewee saw depression as causing a “loss of contact with reality, in terms of just daydreaming”.

Feelings of worthlessness or excessive or inappropriate guilt were not clearly identified as being linked to depression and were seldom described. One participant described depression as having “nothing left ...of your self-esteem” another as “not feeling happy about themselves”. One interviewee aptly described depression as “where the mind and the body lack positive things, and healthy things--feel-good things”. Another described people with depression as having “an inability to cope with themselves and with life (and)their experiences and (that)they live below their expectations.”

Interestingly, suicidal ideation was named by only three interviewees as symptomatic of depression. “Suicidality” or “suicidal thoughts” were described as “inevitable” by one participant and as a “dramatic manifestation” of depression by another.

Other symptoms of depression

Seven interviewees mentioned various emotional states other than sadness as being symptomatic of depression. Anxiety “feeling overwhelmed” or “too worried” was mentioned as a symptom of depression by four interviewees. One mentioned the loneliness of depression “it’s claustrophobic and no one understands; it’s very lonely”. Anger was mentioned by three interviewees along with getting “out of control”. One interviewee was surprised when anger in a family member was an indicator of depression “I didn’t know. I honestly didn’t know that you got angry when you were depressed. To me, depressed is crying and feeling upset. That’s the sort of thing people need to know because, there’s a lot of kids that are really angry or people that are really angry and people just think they’re angry without realising that they are depressed”
A number of participants mentioned an increase in addictive behaviours as symptomatic of depression: “(The person with depression is) smoking more than usual; or they’ve turned to sort of substances. You know, like alcohol”; “sometimes they’ll be looking for a way out of the depression, sometimes it might be gambling or alcohol or just a way to try and lift themselves.”

**Identification of depression and anxiety**

Some interviewees were very aware of the lack of knowledge regarding depression and anxiety in the community: “some people are so educated that they know how to seek treatment. They know how to identify it. And 95 per cent of the Aboriginal community don’t know.” Some spoke about ‘hidden depression’; “I think there’s depression there, from before, and then when people just try and hide their sorrows and if they haven’t had someone with them or if you haven’t had that—caring people—then, you can go deep into it.”

Others spoke about the tragic consequences when depression is missed in the community: “A member of our community, committed suicide…..they used to say, that all they could see was a black cloud—and I couldn’t quite understand that. ......but (they) was saying, like, (they were) going to do that (commit suicide) But you wouldn’t really ...believe it, you know?”; “(they) were depressed for, like, months before that (suicide)—probably a long time. But we didn’t know”.

One interviewee used the terminology ‘silent depression’ to describe what was going on with young Koori people: “and I say ‘well, that’s a silent depression’, we don’t talk about it, those are the ones we need to talk to. If they let you talk to them. Like, you don’t know about it. They won’t tell nobody. They go about their business and they’ll just (kill themselves)”. There was some awareness that attempting suicide was a direct path to help for people with depression “you know, you get these ones that say ‘oh, I’m gonna do myself in’ and all that. They don’t usually do that. ...... it’s attention that they need. They need some ‘help’, ‘Well I’ve gotta do something or attempt to do something to myself before I can get help’”.

**Strategies for identification of depression and anxiety**

The Aboriginal health workers and service providers identified a range of strategies that they used to identify depression and anxiety. These are detailed below and include asking the person if they were depressed or anxious, waiting for the person to tell you that they were depressed or anxious, observing visual cues, noting changes in habits or self-care, using intuition, and for a
few the use of formalised screening procedures. Others simply assumed that everybody who
came in had some level of depression or anxiety.

Some interviewees mentioned that they would identify whether a person was depressed by just
asking them about their mood: “I’d just say to them ‘do you feel sad?’”; “ask them if they were
OK or feeling down too much.” or symptoms: “I usually say, “is your heart beating really fast
now? Do you feel safe at the moment?”

Others stated that they would identify that someone was depressed when that person told
them that they were “some would tell you that they were depressed”; “If someone actually did
come to me and say that they are feeling depressed—not that they’ve got depression, but they
feel depressed—then I would take that as in, yeah, they’re depressed”. One expressed some
doubt over the effectiveness of waiting for people to disclose depression “I know a lot of people
that are (depressed) but, they’re the ones that tell you”

A number stated that they could identify depression through visual cues or observing the
person: “I find with depression, I can see it. I identify it by visual”; “It’s (depression) usually fairly
easy to spot, the eating, the sleeping, just you know the general sadness that comes with
depression”; One indicated that they could recognise depression “just by the look in their face.
You’d see some of them sort of have blank looks and that”. “You can tell by looking at the eyes,
they are sad”; “people yawn”; “I can watch a person they can’t sit still or their whole body,
they’re – especially in depression – they’re all closed up”; “some people will talk fast while others
will just close up. But you can tell (if they are anxious) in their eyes – we look at the eyes a lot and
that actually tells...you can read them where they’re at”; (For anxiety I look at) the way you
speak to me. The way you sit; if you’re fidgety; if you’re looking out; if you haven’t got eye
contact with me”

Two of the participants stated in people that they knew “well enough” that they would watch
for “little signs” or “changes” that might indicate the onset or worsening of depression: “just
changes in behaviour that seem out of the ordinary”. These included changes in personal
hygiene “not showering, or not washing their clothes, or putting soiled clothes back on, or not
cleaning themselves, or not brushing their hair” or “someone who’s clean all the time and you
know, they’re the opposite” as well as changes in routine. “Or there’s little signs—like all of a
sudden you’ve noticed a sign like going to bed, or staying in bed a little bit longer than normal—
or not getting out of bed at all...just forgetting to pay bills—or not paying the bills at all. Or using that money on ... on unnecessary things than ... than just their food”

Intuition was identified as a strategy by one person who then followed up this with yarning “I would be looking out, usually when I talk to someone and if it’s ok, I don’t know what it is but I kind of pick up when someone’s you know not really telling me a lot of stuff that they’re supposed to. And then usually it’s just through yarning that I find out (about) issues with depression in the past.” Another participant described a process which entailed asking people informally about specific symptoms of depression “I identify it by visual. Like, and then I’ll actually ask them how they’re feeling, that they’re withdrawn, blunted affect, they’re tired, maybe too negative.”

A small number (four) of the interviewees noted the use of screening procedures or screening questions to maximise the identification of depression or anxiety. One was confident that depression would be identified because “We’ve got good staff here, who know what the signs and symptoms are...(and) will pick it (depression) up.” Another mentioned the use of a nurse to identify depression “...assesses them about their depression or mental illness or whatever it might be.” Two of the interviewees spoke about asking specific screening question “we ask the questions that are related to depression to find out if they are (depressed).”, “you ask some standard questions, things like, being socially withdrawn and not communicating, and not attending, maybe work or school like they normally do”. According to one interviewee “sometimes it’s (identification of depression), it’s really good. You know, people are onto it straight away, and that depends on the staff ...or whatever.”

Others simply stated that they assumed that everyone that they dealt with had some level of mental health problems: “I reckon it’s probably safe to assume that everyone’s coming in with some sort of form of depression or, anxiety” Others stated that this sameness in experience made it more difficult to identify depression “I don’t know whether a lot of people (are) actually clinically depressed or whether they’re just miserable because of the circumstances, rather than actually clinically depressed.”
Depression causes/precipitating factors

Only one interviewee described depression as being due to a chemical imbalance: “it’s (depression) a chemical imbalance in the body and a medical mental health problem.” Another saw depression as due to genetics “I find a lot of people are genetically depressed”.

There was a broad awareness of a range of trigger factors associated with depression:

“Depression, for a lot of people, can be triggered by different things, it can be environmental; it can be chronic depression that you’re dealing with over long periods; it can be genetic”; “So for me, depression is really an individual’s journey and it’s just all the impacts, it’s the life impacts and social impacts and just geographical impacts as well I would say”.

One interviewee emphasised the importance of understanding the different types of depression in the Aboriginal community.

“(you need to) establish exactly what kind of depression they were going through. There’s all different depressions. You got depressions with, social life. You got depressions with, people managing their health. And then you’ve got the Stolen Generation depression.”

The vast majority saw social and environmental factors as the cause underlying the extremely high rates of depression prevalent in the community. These causes or precipitating factors are detailed below and include trauma being ‘passed down’, the impact of the past, colonisation, discrimination, policies, Stolen Generation issues, the enormous burden of grief, loss of identity and role, social isolation, and separation from community.

Colonisation and the impact of the past

The link between depression and history of invasion and oppression was clearly detailed by most interviewees.
“Well it’s (depression) deeply related to those historical experiences and the loss of connection to land and culture and identity and family. I mean, all of the things that gave life meaning only 200 years ago were taken violently and incredibly quickly and you know we’ve had a whole lot of very damaging policies since then that’s contributed further”

“The triggers (for depression) in my generation are different to the triggers in the young generation. With the younger generation there’s not policies and practices around it...years ago I still remember language—traditional language being taken out of schools and things like that.”

“Trauma, loss and grief was more pertinent in my generation which they say is a contributor to depression....That disconnectedness, that’s displacement. There were policies and practices with our depression.”

“historical issues that have happened in the past that have built up all this time and then it’s like ‘well, what’s the point?’ Hopelessness comes in with it........... they’ve got no future. They feel isolated, they don’t have no one to support them and that’s when the depression sets in........ they’re dislocated from their family and their communities and their lands and everything”

Intergenerational trauma

A number of the interviewees outlined the importance of adopting a “trauma approach” or a “trauma point of view”. A number described the presence of “inter-generational trauma”. One interviewee who had been working in the area told of their own experiences with working across generations of family members over many years “I can see it happening with the families now that I’ve been closely involved with over a number of years and I’ve been working with them you know, three generations in one, now.”
“Most Indigenous people feel it (trauma) on some level. With colonization, it goes back, it goes back many years. And, there’s also with Stolen Gen mob and even families that are victims of domestic violence and all that kind of thing. It passes on to the next generation. So, trauma is really, is pretty huge in Aboriginal community. It’s all that they’ve ever known. So they think that’s just their life. That’s, that’s normal lots of people don’t understand, either, that trans-generational trauma stuff. They think ‘if it happened to Mum and Dad, then it … it didn’t happen to me’, but they’re not aware of how …how that comes.”

A number of interviewees spoke about the inheritance of trauma “But, it’s like the history of that person, when you go back, from their mother and father” A history of exposure to domestic violence as a child was also thought to be part of the trauma that is passed down the generations: “I think there’s trauma somewhere in their life that impacted and if it’s not them then it would be a family member or someone and then that’s been passed (down).”

“We got a lot of young ones …they’re going through trauma as well because it’s been handed down, from their parents as well.”

“Things happen to them when they’re kids and then years later this all comes back to haunt them. There are all sorts of things (that come back)”

“Your grief and trauma, and that’s what’s so different with the community and when you have those two things, it sits and sits and sits and doesn’t go away until there is healing…until the healing comes the trauma doesn’t leave.”
Stolen Generation trauma

Many interviewees spoke about Stolen generation trauma as a cause of depression:

“If they give you a history and they’re Stolen Gen mob there’s all this trauma in their life in their past.”

“We’ve got an abundance of Elders still going through, Stolen Generation Trauma”

“Stolen Gens that’s the first thing when I hear (depression), especially in the community. A blackfella will say ‘I’m really depressed. I don’t know why! Why do I wake up crying?’ because they don’t know because they come from a Stolen Gen. That’s one thing. Stolen Gen that wipes a lot of our people out—because of that. That self-esteem. And when you don’t have an identity, your self-esteem is gone.”

“What I’ve also come to realise and work with in the community is—around depression—is that it’s, it’s the Stolen Generation. It’s what triggers off the drinking and the alcohol and the sexual abuse. So those, those commonalities, they all go hand-in-hand.”

Lateral violence

Many interviewees named many types of violence including lateral violence as being both a symptom and a cause of depression in community members:

“It’s (lateral violence is) all part of your everyday life. And our community, there’s a lot of lateral violence and there’s a lot of depression and anger.”

“Child abuse does bring a lot of that depression into it, trauma, ‘cause all the clients that we do deal with probably had sexual abuse...and also from domestic violence and all that. It’s
everything......that’s a big issue in the Aboriginal communities,
...domestic violence, it causes a lot of depression and suicide.”

The inheritance of loss

Many interviewees spoke about the multiple losses that Aboriginal people had experienced and how this created a culture of depression and ill health and “depressed lives in general.”

“The people who’ve shared the difficulties in their life and they’ve often been around violence and abuse and loss of identity, loss of family, loss of everything. I think some people they’ve just had terrible lives from very early ages. They’ve had a whole lot of traumatic experiences and very few people that they can rely on.”

Grief and loss

Many interviewees were clear that in the Aboriginal community depression was akin to grief and loss with complicated grief arising through multiple, ongoing losses: “Most Aboriginal people have a lot of deaths in one year. I had one staff member who had many, many deaths so you never rise out of your grief. It actually sits on your shoulder all that time”; “there’s an anxiety state and they’re doing abnormal things to compensate for the loss of the many people.” In addition to the impact of multiple losses, the grieving process was also demanding “our people die and our grieving process takes weeks, months, years.” The connectedness of the community also increased the burden on the individuals through shared grief and loss:

“It’s the extended family. Because with our Aboriginal extended family, when there’s one problem in one area, there is a ripple effect. So when there’s a funeral everybody gets affected.”

This connectedness was also seen to be a supportive factor in dealing with grief and loss:

“the burden of that grief was off-loaded on the entire community, they all felt the pain, so everyone carried the bit and they will do that for a long, long time together. And in a way,
“that’s what the Aboriginal community does, a lot gather and they will still talk about it and gradually it will dissipate away”

Identity and role challenges

The interviewees saw depression, anxiety and other mental health problems as being related to loss of gender role, in particular for males in the community: “We’ve gotta understand too, with our society today, we’ve got Centrelink, so women don’t need the men to go out there... They’re just feeling that they’re not wanted...and Aboriginal women are more likely to be employed and better-educated than men. And the men are just feeling left out...it all links up with depression.”

“There is a lot of depression that comes out of it (loss of identity) because they feel that they’re just lost—because nobody’s managed to help them.”

Loss of identity was seen by some to be the main driver of problems with social and emotional wellbeing:

“whether you call it spiritual or cultural or emotional and spiritual around your loss of identity and loss of connection. So loss of identity could just about stand on its own you know, cover that emotional and spiritual well-being”

Life challenges

The pressures of the life lived by community members seen by many to be a key driver of depression.

“It just seems to me that everywhere you turn and everywhere you look—the way the world is—there is more pressure.”

“From my experience—what I’ve seen—our people, they just can’t cope. Things that have happened in the past and it just affects them and then they can’t cope with society today.”
Carers were seen to be shouldering a heavy burden:

“You look at all the Grandmothers and the Mums and Aunties, we got a big load. They care for them all. And all the pressures of their family brings that anxiety, brings depression in a lot of cases”

“because if somebody’s looking after them, a daughter is looking after the mother they get depressed, because they get sort of isolated, 24/7 caring...They don’t get to have respite.”

“They (carers) need to have and get away from the house, you know. Whether it’s partners or not, they need to be happy and go away and just enjoy things because they belong to us in this community as well”

“Sometimes Elders in the community are so busy being strong by the time we seem them, they’re wrecks. They’re so busy carrying the community on their shoulders. And women carry, you know, families on their shoulders and other people in the community, they carry, it’s an awful lot, really. No wonder. When you hear the stories, you think ‘no wonder’. why wouldn’t you be depressed? Why wouldn’t you be anxious? Yeah, they carry the whole community.”

Financial pressures were mentioned by many as leading to depression and anxiety:

“Now depression is coming up because life is just lot harder and more challenging. Financial—things are going up in prices. You know, like rent and food and ... just to stay on top of things. They can’t cope.”

“That’s, that’s another big issue, the anxiety. People are anxious for everything. And it comes through food securities, all kinds of things.”
"just those day-to-day pressures, you know, how are you gonna feed your family? How are you gonna pay your bills, you know, it’s just everything."

Relationship stresses were also highlighted as leading to depression:

"a breakdown with a relationship...if it’s not addressed straight away it can go on and bigger, get bigger. And it affects, not only that person, family but other community members and family”

Social isolation

Social isolation was identified by many interviewees as leasing to problems with social and emotional wellbeing in the community.

“So many of the people really are very isolated, even though families are still strong, a lot of them are quite fractured and people have moved out of area. And I’d say the majority of community people I’ve been in contact with have very few supports from either families or friends; so you know that Aboriginal people have fewer supports outside the immediate family then non-Aboriginal people do just because of that dislocation and dispossession.”

Out of Country

For Aboriginal people a long way from their own community and culture the isolation and challenges that they were facing were seen as more extreme: “people coming off Country don’t know how to access anything in this city...(they’re) feeling so overwhelmed.”

“Geographically, we see patients from interstate, it’s just being out of Country. They’re so quiet and reserved...Melbourne can be frightful for someone from a remote area or from another city coming here and not knowing anyone.”
“If you've had you know mental issues up there (in your own community) and you haven’t been treated and you come down here and you don’t know anyone. Of course it’s going to flare up and get worse”

Role of Wurundjeri

The need for Wurundjeri to Welcome Aboriginal people from other Country was a strong theme in some of the interviews:

“Some of them are from Country and for the Wurundjeri to respectfully acknowledge others from other Country and being welcoming is actually critical for any traditional peoples... you still have to welcome and acknowledge and respect the country where they’ve come from.”

“I think Wurundjeri have a vital role in that they’re trying, this is Country and they’re trying to bring in culture. And so you’ve got to find out what are the connecting points that will make people interact again.” Interviewees emphasised the importance of “Traditional Owners really taking responsibility about caring for people and country”

One of the interviewees elaborated on this theme by commenting on their own reaction to being Welcomed by Wurundjeri: “I know that I’m Welcome on Country, because they’ve made me that”. Another stated the importance of identifying their people: “coming down here, the first thing I did was just go out to the shopping centres looking for my people even though they’re Wurundjeri. But they’re still my people”.

The responsibility of Welcoming others from off Country also weighed heavily on the shoulders of some of the Wurundjeri people interviewed:

“[We want] to make them feel Welcome and comfortable as well. As a Wurundjeri woman, I know what it’s like to be on someone else’s Country, you don’t want to go in feeling unwanted,
especially in hospitals. That’s when you need the support the most.”

“We’re Traditional Owners, really taking our responsibility about caring for people and Country seriously.”

Depression and anxiety leading to chronic disease

Interviewees noted that many patients or consumers that they saw with a chronic disease also had mental health issues that had impacted on their health. Some believed that the mental health problems directly led to the chronic disease:

“Depression can cause chronic disease, because people don’t look after themselves, don’t eat right, don’t take care of themselves.”

“I think definitely mental health (problems come first), then chronic disease”

“cause often their physical sickness has come second, because they’re so emotionally and mentally unwell.”

“you just need to look around the community. You’ll know that there is that problem; there is that problem; there is that problem that’s there. And those things are bound to impact on people’s health. It (depression) has to. It’s bound to, have some play in your life.”

“Oh well, I think it (anxiety) directly affects their blood pressure you know; it’s quite blatant some of them have the most shocking blood pressure. It can upset the digestion directly as well. It can have direct sort of physical impact”

“I guess anxiety can cause us quite a disability because it can cause you quite physical health problems too because you’re not breathing properly, you’re not … you’re tensing up your body all
Many of the respondents emphasised that pre-existing mental health problems led to poorer health outcomes when confronted with the challenges of a physical illness if these issues were not addressed:

“When (an Aboriginal) person has chronic illness, they will deteriorate rapidly. It’s very quick if those mental health issues aren’t dealt with, I mean so rapid that they’re in a grave before you can blink an eye.”

“If they have mental health issues, they really need to get that sorted out quick smart with people that are supportive. Because you can’t ... move past that with the chronic stuff ... because people will sit at home and they’ll just ‘oh, I can’t.’”

Patients’ willingness or capacity to adhere to treatment plans and their capacity to make illness management a priority was seen to be greatly affected by mental health issues. One interviewee remarked “look at everything that’s going on. Of course it’s (physical health is) important, but, for them ... their emotional wellbeing is, kind of, more important at the time”. Another asks us to consider the real enormity of challenges faced by Aboriginal consumers with a chronic disease:

“Imagine layers and layers of medical problems and being a single mum and you’ve got a—one list, two lists, three lists, four lists ... ‘oooh, too much. Oh! I’ll just go to sleep; wake up if I wake up.”

Others remarked on the unique cultural challenges faced by Aboriginal people living with a chronic illness:

“Everyday, for a person with chronic illness, everyday is a challenge. For an Aboriginal person (with a chronic illness) in terms of how are they different, I think the influence of the cultural the sense of belonging to place and cultural events and
knowing about how our ancestors tackled things in the past, that sense of pride is very strong. That sense of responsibility to community is very strong.”

“The increase in pressure about your health; the care and concern for those around you. You know, if you’re the matriarch of a group, then you’ve not only got you, but you’ve got this whole group. It’s the type of thing, then, that builds and builds pressure”

“They feel like they don’t wanna get treatment. They feel like an invalid ‘cause they’re getting treatment all the time. I think Aboriginals just, they’re not really into doctors. I reckon there’s a big concern with that. Anytime they can avoid going there, they’ll … Unless it’s life or death, they don’t really ever go, really”

Interestingly their also seemed to be a ‘catch 22’ position around treatment in particular for Aboriginal men with a chronic disease which would lead to shame regardless of whether or not they followed through with treatment options for a chronic illness:

“well they think that people will judge them, look down on them, if they don’t go and get treatment. The Aboriginal men-folk, they’ve got this image—that if they go and do this, then people will think less of them. They’re weak”

**Impact of wellbeing issues on chronic disease management**

Mental health issues impacted on many aspects of disease management including accessing or continuing with medical consultations, lifestyle behaviour challenges, adherence with medication as well as just being able to make their disease a priority in terms of self-management.

Interviewees frequently observed that for some patients, their previous trauma history impacted on their willingness to turn up for treatment for their physical illness:
“Particular with the Elders around the Stolen Generation, that building might remind them of someone that was taken or where they lived fostered out into institutions. It could be someone in there reminds them of something that it’s enough to impact them, create that anxiety, they’re gone or they won’t turn up.”

Another interviewee talked about some of the challenges associated with discovering the barriers to care:

“sometimes they won’t go to the doctor and you’ve got to find out why and is it because they’re anxious about something? What is it? Is it that doctor? Is it that surgery? Is it something about that environment? Do we need to shift you to another doctor, another surgery?”

Low treatment adherence in Aboriginal people with depression or anxiety was a concern for many interviewees. Some interviewees were clearly aware that many health professionals lacked understanding of the impact of depression on treatment adherence:

“a lot of people don’t understand, with depression, the biggest part is compliance”.

“Sometimes they can’t, can’t work out how to take the next step and how to manage it. Taking medication and medication regime, that’s huge. I find that health professionals use the word ‘non-compliant’ with people who have chronic disease or illnesses. They’re non-compliant because of their depression”

I find services and people who work in the services forget about that (mental health) when they talk to the (Aboriginal) client. (They) don’t really try and help them with that part. No one looks at that part in treatment. They’ll say ‘oh, she didn’t come to her appointment today. Oh well ’… They’ll make judgements. Instead of saying ‘hello dear, how are ya? How come you didn’t
come?’ They (health professionals) do it all the time—especially with heart disease. They judge people all the time.

A major challenge mentioned by interviewees was just getting Aboriginal people with depression or anxiety to participate in their own care:

“People don’t take their medication, they don’t go to appointments. They don’t cope with simple things. Taking medication is the biggest problem – because it’s a change of lifestyle.”

“Anxiety in a lot of ways has made a lot of patients unable to come in for care, (anxiety) gets in the way because they get something in their mind and they get so nervous about it; it’s like a bad seed gets planted in their head so they’ll be so anxious about this thing happening that they end up making a decision not to come in and have their care”

“It’s really hard to get them to go and to get them to the doctors, to motivate them to learn and or to get them to go to the appointment or to keep appointments is really difficult and often it would mean us picking them up and actually taking them ourselves.”

“trying to get them to come into appointments and also supporting them through that is very difficult but also trying to explain what the care they need. And half the time I find that it is like they’re not mentally in a well place to deal with it”

“(depression or anxiety) makes them non-compliant with their medication, looking after themselves, you know, complying to what we’re trying to get across to them and follow. There’s further steps that they need in managing their chronic diseases. They just don’t worry about it. It’s not important. They don’t,”
they don’t see why they should be doing it because, they’re gonna end up here anyway, so ‘what’s the point?’”

One interviewee observed that, if mental health issues were addressed, this markedly reduced the barriers to management of the physical illness:

“If their depression is managed and treated and assessed early and they’re on the right sort of medication, if something else crops up, they can deal with it. It’s not great, but at least they can deal with it.”

“When you have anxiety, your brain says to you things are maybe 50 times worse than they really are—and you’re travelling that speed… I don’t believe that they could take it (a diagnosis of a chronic illness) on board, if they were told they had diabetes. Oh my God! They’d be imagining the worst outcome. So obviously, if people had anxiety the first thing you do if they had a chronic disease, is you try and manage that anxiety…. Your chronic disease actually gets worse if you don’t treat the anxiety. The mind doesn’t think straight”

**Impact of chronic illness on depression anxiety and related disorders**

Aboriginal patients or consumers with a chronic disease were seen to have even greater issues with social and emotional wellbeing than the broader Aboriginal community.

“Most of them that come here have some form of mental illness, and a lot of it (depression and anxiety) is due to their (chronic) illness… but also a lot of it is (due to) their history book.”

Chronic disease was also seen as a ‘breeding ground’ for depression and anxiety: “When you’ve got somebody with a chronic disease, there’s always associated mental health with that as well” ; “Chronic disease is something that breeds depression because you know there’s no cure for it”.
“you probably(are) going to get anxiety with chronic disease, because chronic disease, you don’t really know where you’re going. There’s no cure for it…. there’s no solution, there’s no real way of telling what’s going to happen tomorrow. Are you going to feel good tomorrow or are you going to feel crap? what’s going to happen. So, I guess anxiety goes hand-in-hand with chronic disease.”

Resignation was seen to lead to a demoralisation associated with having a chronic illness:

“A lot of the community members … will just give up in the end and just go with it. It’s like they feel hopeless that ‘oh, look, there’s no use in managing it (the chronic illness) and doing a really good job. I’ll just … I’ll just enjoy the rest of my life. And if I eventually die, well, so be it, because it’s gonna happen to me anyways.’”

“They just don’t want to do anything, they don’t wanna get out of bed; they don’t wanna try anything different; they don’t wanna! It’s like I can’t … ‘what’s the point?’ You know? It’s like hopeless, endless…”

“And then a lot of them just don’t care. They just think ‘oh, well … if I die, I die’. Like, it’s sad.”

“A lot of people just give up and they just can’t be bothered before they even get there. It’s just too hard. It’s like ‘well, you know, I’m gonna die anyway. What’s the point?’ Or ‘what are they gonna do?’ Or ‘how are they gonna treat me?’ Or, ‘I’ve got all this stuff happening at home. I’ve gotta deal with that. That’s more important’. You know? Or ‘I’ll just put it off.”

“The anxiety could be with the denial and it can be with the anger. Some of them are like ‘well who cares?’ Like, one the other week—was gonna pull the tubes out. He’d had enough. He
doesn’t care if he goes home and dies. He was angry that day and very, very anxious at the same time.”

Fatalism associated with the poorer life expectancy of Aboriginal people was seen to lead to helplessness and hopelessness when faced with chronic disease:

“In the Aboriginal community—you see a lot of deaths.... A lot of Aboriginal people, they don’t live to that age (50-60 years). And they talk about Aboriginal people die 20 years before other Australians. I think the worrying thing is the cycle in the Koori community.... I’ve actually heard some people mention it. Like, say it in a health setting. Say ‘oh, well. You know? We die 20 years before everyone else. So who’s gonna worry?’ My mother and father died at a young age because they had this and that. And that’s the way of life of Koori people and ‘we’ll, we’ll just go with it’.”

“some of them might just give up on their positiveness of managing diabetes and think ‘well, what’s the use? You know, I might as well just go and buy another slab and go out with the boys and party on and just be done with it.’ ...I’ve sort of experienced it, seen it amongst younger and older. They’ve sort of resigned to the fact that ‘oh, well. You know, I might as well just go with the flow.’”

Interviewees were aware that the demands of adhering to a challenging treatment regime also led to depression:

“she gets depressed at having to always stay on top of it. Checking her sugar all the time and stuff. Like, you just see her. She hates having to always worry about getting her legs chopped off and that. She doesn’t really look after it that much. No, a lot of the mob don’t.”
Resilience

Some of the interviewees spoke about resilience with one talking about struggling rather than serious clinical depression: “not everybody’s got depression. I’m just thinking about the women-folk out there, struggling. It’s just struggling to have food security stuff, proper health and all that.”; “depending on how much resilience or how much good luck people have in their lives as they get older as to whether they have manageable amounts of depression or something that becomes really debilitating.” Family support or resilience of spirit seemed to be key factors:

“There are other people out there who got chronic health who don’t get depressed you know. They seem to be resilient sort of spiritually, emotionally, whatever”

“There’s a lot of chronic diseases now and there’s depression with it. But I think there’s a lot of chronic disease too that, that they don’t have that depression, they’ve been able to look after their families.”
Methods Study 2: Consultation with the client group

Study Sample: Client Consultation

Eligible participants were Melbourne based Aboriginal community members with chronic disease and experiencing depression, anxiety and/or related disorders.

Sample size

Based on initial consultations with the founding Steering Committee members, it was anticipated that conducting approximately 6 focus groups (N=50) would be possible during the second phase of the project. This initial estimate proved to be overly ambitious, with the project team being able to undertake 3 focus groups, or ‘yarning circles,’ and several one-on-one interviews with the client group who were either unwilling or physically unable to attend groups (N = 17).

Procedure Study 2: Client Consultation

Participant recruitment

A multi-tiered approach was adopted in the identification and subsequent recruitment of eligible participants, including: (1) individual consultation with each of the Wurundjeri Wellbeing Team members; (2) individual consultation with grass roots members of the Wurundjeri community; (3) individual consultation with grass roots members of the broader urban-Aboriginal community; (4) word-of-mouth i.e., urban Aboriginal community peer-to-peer networks; (5) a direct request for assistance with recruiting eligible participants at the second Project Reference group held on the 8th of February 2012; (5) the distribution of an invitation with an associated project flyer detailing project eligibility to the 33 recognised Wurundjeri Elders; and (6) the distribution of an electronic invitation with the associated project flyer to relevant services, including those services that had actively participated in Study 1. An example invitation to organisations of high project relevance (Appendix IV) and an associated flyer (Appendix V) are appended. One community controlled organisation, the Victorian Aboriginal Health Service (VAHS), requested that an Application for Research be
submitted to their Research Subcommittee for consideration. An application was subsequently submitted and after consideration, rejected by VAHS.

One organisation volunteered to provide access to an appropriate community group during the feedback session on the day of the second Project Reference Group once it had been clarified that community would be remunerated for their contribution. Another organisation responded positively following the distribution of the electronic invitation and flyer. One service provider interviewed as part of Study 1 also happened to be independently affiliated with a Women’s Group and contacted the Project Manager following the distribution of the electronic invitation and flyer. Several members of the Women’s group who were unable to attend on the day of the yarning circle provided their telephone details to the Project Manager who was able to interview these participants via one-on-one interviews at a later date. One Wurundjeri Elder (not directly associated with the project) contacted the Project Manager to arrange a one-on-one interview.

The members of the three groups that participated in the project comprised individuals who, while not related, knew each other extremely well. Either one or two members of the Bundap Marram Durn-Durn project interviewing team, typically either Ms Karmen Jobling and/or Aunty Diane Kerr, travelled to the location specified by the participating community at a time that was identified as convenient by the community. All participating community members received a Coles Myer gift voucher to the value of $50 in appreciation of their time and contribution to the project. The duration of yarning circles ranged from 60 to 120 minutes, with most yarning circles being an average of 75 minutes in duration. Individual interviews were comparable in duration with the yarning circles. The Project Information Sheet (Appendix VI), Project Consent Sheet (Appendix VII) Focus Group Schedule (Appendix VIII) are appended to this report.

Data analysis and interpretation

After transcription, the interviews were analysed by Dr Higgins and Dr Murphy using procedures recommended by Patton (13) for themes relating to the client groups experiences of a) the onset and experience of chronic disease; b) the types of services used to manage health; c) barriers and enablers in accessing service to manage health d) experiences of depression; e)
experiences of anxiety; f) gaps in services; and g) reflections on types and services and/or programs that could generally enhance wellbeing. An inductive approach to content analysis was used to allow the themes to emerge from the quotes (13). Interview tapes were listened to and transcripts read repeatedly to ensure accuracy and to include relevant information from field notes (e.g., pauses, laughter, overall mood of participants). The basic unit of analysis was defined as quotes from the transcription that represented the experience of the client group as it related to the categories a – g as identified above. Quotes were clustered with other quotes with similar meaning, forming raw data themes [13]. Raw data themes were inspected for overlap and commonalities and, where appropriate, merged together to form higher-level themes. Higher level themes were labelled ‘first-order themes’ or ‘second-order themes’ accordingly with the highest level themes labelled ‘general dimensions’. General dimensions represented the highest-level, where no more themes could be uncovered. Interpretation of the data was conducted under the supervision of the Associate Investigator Aunty Diane Kerr, to ensure the cultural appropriateness of data interpretation.

The results presented here draw on the qualitative data analysis undertaken to date. Further qualitative findings will be available over the next 12 months.
Results: Study 2 Client Consultation

Study sample

The sample comprised 3 yarning circles and several one-on-one interviews totally 17 urban-Aboriginal female service users.

Themes arising: Client Consultation

Chronic disease and depression or anxiety

Chronic disease had an enormous impact on the participants’ wellbeing. Participants noted a range of social and emotional wellbeing issues in relation to their chronic disease including exacerbations of illness “if I stress out too much I get that thing. I forget what it’s called—where your skin builds up (eczema)”

Many reported depression anxiety and other mental health issues as stemming back to childhood: “Since I was, like, in my teens and even before that I was suffering from depression and anxiety.”

Many reported issues with sadness or worry regarding their chronic illness “I feel as though I’ve got no energy. I feel like all I want to do is go out and cry. Yeah. I feel as though I’m all alone”. Others were clearer in reporting that they had depression: “I’m suffering from depression and that’s what I wanted to talk about. Depression.” In the focus groups many participants recognised that they were “suffering from depression”. Some reported increased feelings of frustration and anger.

Management of depressive symptoms was a challenge for many: “If I’m not happy on a day it’s just like you wake up lately I’ve been waking up and sitting there and just not even talking. I just like being quiet, ’cause you don’t get into arguments.”

Participants noticed frustration with limitations to their functioning and mobility “I’ve been frustrated ’cause I can’t do things. Like when I get down I can’t get up”. There was a lack of clarity as to the relationship between emotional symptoms and physical health: “I’m feeling really cranky lately. Does that relate to the health?”
Mental health diagnosis were reported by community members, with some illnesses undiagnosed and untreated for years “last year they diagnosed me with bi-polar two. And that’s ever since I was (very young), I’ve had it—but never been medicated. And wondering why I’m so high. Like, I’ll be buzzing around ... buzzing around like I’m on speed and everything and it was actually the bi-polar.”

There was lack of clarity and understanding around symptoms regarding which whether these were a mental health issue, cultural reaction or a byproduct of trauma:

“I get to the stage where I lock myself away. I don’t talk to anybody, I don’t answer the phone, I don’t eat. Is that a black thing is it? ‘Cause I know a lot of black women that do that. I know a lot. ... Just the culture, I s’pose.”

“I think it’s just the way the mind works. That’s it. (The mind) shuts down really slowly. When you’re down and out and things are not (good)”

Depression also led to a falling away from culture which became another loss “because of my depression, I fell away from my culture, I fell away from my Elders, fell away from everybody—and I felt I needed that. So at the time I needed that, and I needed to be with them”; “No, it’s not culture. It’s the strength. They give you strength that just ... the way they talk and (what) they’ve been through it. And they look at things in a different way to us, now.”

**Family members with mental health issues**

Many reported multiple family members with mental health issues “it doesn’t help that, you know, my mother and my sister are both suffering from depression too”. Others expressed concern about genetic heritage “Well that’s what I’m worried about... they say there’s a big chance he’ll carry a gene (for mental illness) ... It freaks me out thinking about that.”
Suicidality

Some community members spoke of suicidality: “like you get to that rock bottom where you just want out.” Links between grief, lack of support and feelings of suicidality were also recognised: “I was still going through a lot of grieving with my father and stuff and ... depressed, and my partner at the time, he was going through his own thing so he wasn’t really helping me and ... the only thing I could see is ... the only thing I could do to help was to go home and see my dad. So I wanted to jump in front of a truck or a bus (to be with my dad).

“A number of community respondents spoke about suicide attempts “I took a thing of sleeping pills. And they found me unconscious, and I was in the hospital.”; “it’s gotten to the point where I’ve tried to kill myself three times.” This was normalised by others in one of the focus groups: “We’ve all done the suicide thing. I think we’ve all done that...”

Many of the community respondents reported periods of hospitalisation in in-patient psychiatry units “I had suicidal thoughts and around about last year I tried to kill myself. And, yeah, I told my counsellor and, yeah, she put (me) in the psych ward. It was sort of hard being there and, yeah, getting off the drugs and the alcohol.” ; “cause before that I was on the wrong anti-depressants and they wasn’t helping me. Then once I’d got in the ward, the psych ward, they got me on the right meds.”

Managing depression and anxiety

Managing day to day life along with depression or anxiety and a chronic illness was a real challenge for many of the community members: “I wasn’t coping, so I wasn’t managing with the day-to-day things. And the anxiety—I wouldn’t leave the house without someone else.”

Others were using a range of strategies to manage depression: “I just sit here and talk and listen. I watch movies. I don’t really want to go into tablets. But I deal with what I can.”; “I’m getting a foot in front of the other one, but I stumble every now and then and I go back. But I’m doing it on my own and it’s very hard.”
Causes of depression

Past experiences were seen as leading to destructive coping which was then seen by others as a mental health issues:

“I keep saying to them ‘in my heart, I don’t believe I’m mentally unstable. I didn’t ask to be the way I am.’ It’s what’s happened to me in my lifetime that’s made me the way I am. It’s put up a guard; it’s broken all my barriers. It’s been all the defensive and non-defensive things that I’ve had to deal with in my life that’s made me how I am—and I don’t believe, in my heart of hearts, that it’s a mental issue. It’s the coping mechanism that we’ve had to deal with that’s made me (what I am)”

“My mind shut down because I’ve just gone through a big hell in my life”

Trauma was seen as leading directly to depression, particularly childhood trauma. Many had awareness that these traumas were “building blocks” for mental health problems: “with depression, it’s really stemming back to my childhood. That was the first hit I got” A range of traumatic experiences in early childhood were mentioned by the community respondents: “Child abuse physical, mental, sexual … everything….”; “I used to get sent to school black and blue.”… “Yeah, same.” Some reported that childhood memories of abuse were coming back as they aged “I’ve found at as I’m getting older, too … I’m remembering more of my past, which is haunting. And … and I need ways to deal with that.”

Violence in relationships was also mentioned as a cause of depression: “Then as you get older, you fall in love and there’s abuse, again of all shapes and manners (making depression worse).”

Grief, fresh, buried or omnipresent was a continuous theme amongst the community respondents and was seen by many as a cause of depression. Community respondents reported carrying a large burden of grief, with many reporting themselves to be “still grieving.” Respondents spoke about the burden of “living with constant death.”; “Living with constant grief” and “just waiting for the next person to die” One reported on the grief of adoption: “I’ve
had pretty much depression on and off all my life. It’s I suppose, yes, stemming from being adopted and then things that have happened in my life.”

Many reported old griefs that were still affecting them. In particular maternal loss continued to affect people many years down the track: “I’m feeling really, lately that I’m depressed over mummy’s death. It’s (more than 10) years this year for her death. I’m really missing mum.” “23 years ago, but with mum it’s like yesterday. Your mum they’re important people in your lives.”

**Being the strong one**

Having to be “the strong one” or the “matriarch” was seen by women as ‘part of life’ but also a cause of mental health issues: “You’d just keep it to yourself”; “You always keep a happy face no matter what.”; “I’m a tough b****! Ha, ha, ha!”; “I’ve been bouncing back. When you fall down, you bounce back up.”

“You don’t worry about yourself. You don’t care about yourself”

“Women have been brought up to be the strong ones in the family. So regardless of what happens to us, we’re always gonna be there at the end of it.”

“I just think as a cultural person, that’s what we do (cope). We’re such a resilient culture”

“The way I’ve been brought up is the grandmothers, the aunties, the uncles … you look after everybody in the … it doesn’t matter. If you’ve got your problem, you’ve still got your family and you’ve got to take other people in. So you’ve got to deal with all that. So we’ve learnt … we’ve learnt to be strong. We’ve always been that strong-headed black women.”

“I’d get a phone call from my kids, and if I had to get out of bed at 3 o’clock in the morning, I’d be gone.”
“You’ve got to try and be strong and try and get over it (depression) yourself”

This cultural pressure to be “the strong one” was seen as problematic: “Cause we think we’re strong enough to deal with our problems ourselves, but we’re not. We can fall down.”

“I find it really hard because I’ve come from an Aboriginal community you feel all these other pressures. ‘I’ve got to do this and I’ve got to do that; and I’ve got to be there for that person; and I’ve got to make sure that that’s done for that person and like, life’s just so full-on and so busy and so over-the-top. ‘I’m sick of you can’t do this ‘cause of community or you can’t do that ‘cause of community; But that was what I was brought up with, is that you take care of your community.”

This pressure to be the strong one or to cope was evident for some in the lack of readily available family support

“I’ was too embarrassed to ask my family (for support)”; (I am) scared of being judged (by family).”

“They don’t really help and support you... they don’t understand what you’re going through.”

“well if you ring them (family) and tell them all they’re going to do is rip the shit out of ya...or they just say ‘oh, well snap out of it and ... ‘you’ll get over it’, and that. But you can’t ‘snap out of it.”

Caring responsibilities

Caring for children while managing depression and chronic illness was challenging. Some felt like they had been unable to fulfill their parental responsibilities: (I was so unwell that) my kids were there and they were ... sort of fending for themselves.” Others were worried about the impact of their illness on children “Because emotionally it distresses them, because you’re, like,
the strong one in their life and as soon as they see you weak, they freak out. When I’m in pain and he sees me cry—he freaks out because here’s this invincible person to him suddenly worse off than him, weaker than him. And it affects them.”

Some expressed a fear of passing depression down to their children:

“It’s dependents—or people that look up to you—ones that don’t know the world yet. You’re teaching them the world, and if that’s what they see the world is—pain and suffering—they’re going to go into depression, they’re gonna try to kill themselves by 15 because of fear.”

For the grandmothers, responsibility for grandchildren was seen by some as a motivator for staying healthy: “I need to have my strength and my body, because I’m going for custody of my three grandchildren and I need to be one person.” Being a single grandparent caring for a grandchild was seen as a source of real pleasure “Do you notice it’s better now, being single, and having grandkids?”; “I’ve got my grandchild living with me now, and I live every morning to see her—every morning.”

**Relationships**

Intimate relationships were often seen as adding to the burden rather than as a source of support: “I was more of a mother to him than a partner. ...it was just getting to me. I’ve got enough to deal with”; “I had the same situation, a chap that I was seeing. I was more like a mother-figure to him; and he was older than I was. And in the end, his care was more important that I was—more important than anything.”

Physical and emotional abuse in relationships were seen as leading to worse mental health problems: “It started last year and a lot of people could see me going right down. And I ... I try to keep my strength and that, but I couldn’t. And that’s when I had to go into respite care. And it was all because of my partner—that was why I was like I was.”;” They (partners) play games with you. Once they know you’re vulnerable, they pick at you. And they pull and get you.”; “I felt weighed down all the time. I had no energy; I was in bed all the time ... wasn’t I? I wasn’t going out; I wasn’t doing nothing ... He was just bringing me down.”
Health appointments were hard to prioritise amidst a background of relationship disintegration

“I haven’t been (to the doctors) because of what I’ve been going through with all this crap at the moment. So once I get all that out this week I’ll make my appointments again. I just want to focus on one thing.”

Grief and loss

Some spoke of ‘battling through’ the journey of grief as though trying to reach an undisclosed destination: “I’m trying to get there.” Others were clear of the need to just ‘cope’: “It’s hard. But you’ve just got to ... they’re not there anymore, so you just deal with it just talk to them. That’s what I do.”

Funerals and cemeteries were seen as important “I need to go to the funerals ... what do you call it? I need to go to the grounds, the cemetery. That’s what I’m talking about.” Others had lifelong regrets that they had missed funerals “cause it was too sad.”
Needs Identified: Synthesis of Study 1 & 2:

**Service Provider and Client Consultations**

Analysis of all interview and focus group data from service providers and community members revealed a number of areas of need that could be addressed by the Wurundjeri Tribal Land and Compensation Council to improve the wellbeing of Aboriginal people in Melbourne with a chronic illness and depression anxiety or a related disorder. The Land Council is not a health service, so needs suggested by respondents which focussed on the direct delivery of clinical health care services were not included in the identified needs. The data collection identified a number of key areas of need that could help Aboriginal people who have a chronic disease and depression or anxiety.

- Need for cultural connections
- Need for community
- Need for pride
- Need for healing
- Need for information
- Need for someone to care (case management and intensive support)
- Need to welcome and be welcomed
1 Need for cultural connections

A number of the respondents mentioned the important role of the Wurundjeri as a custodian of traditional culture “Wurundjeri have a vital role in that they’re trying, this is Country and they’re trying to bring in culture”. Connecting to culture was seen as a vital part of healing both physically and mentally “Once they connect to culture, it’s a healing thing.” There was a clear belief that if people “don’t know what their culture is” then “they don’t know who they are.”

“being the minority, it’s very hard to sustain who you are and what you keep and treasure”

“We have to really, where can we, wherever we can, reintroduce or reclaim our culture in what we do. Reclaim it and have it embedded in things we do.”

Maintaining traditions and reviving language were seen to be part of creating pride and a healthy community “There’s a lot of traditions, a lot of stuff that has been lost and language is one of it. It’s great that there’s organisations like the Wurundjeri council and the language centre that they’re trying to revive a lot of that and it’s really important that they do.”

Need to “know our story” through increased understanding and connection with “cultural objects and artefacts” was also expressed. This included knowledge about and familiarity with “cultural artefacts”.

Respondents identified a need to “know our history” through opportunities to participate in traditional activities including traditional arts and crafts as part of connecting with culture and connecting with community. This might include “beading”, “arts and crafts”, “weaving”, “feathers & flowers”, “basket weaving”, “boomerangs”, and “painting” as well as a range of other activities.

2 Need for community

“Everyone needs to be connected. Some way and they just know it within themselves”
Many respondents saw connection with community as an important part of healing: “when the community are involved with each other life’s a lot better for them”

“We can help contribute towards making people feel stronger and healthier just by reducing their isolation—social isolation—and lack of connectedness.”

“Engaging with the community, getting people more culturally aware and connected to culture” was seen as a key component of improving community life and so the welfare of Aboriginal people with a chronic illness and depression or anxiety: “What our people long for is family, home and where they belong”

Respondents were aware that “(people need) encouragement to participate in community life so that they have some sort of social connection”. “I think the focus has got to be on something that they want to come for enjoyment, not for their health usually”

While some bemoaned the lack of community activities “honestly, there really is not too many opportunities for people who wanna sort of, maybe, come back into the community, or to get out of the house and do something. What are you gonna do? Where are you gonna go? So there’s not a lot happening. Let’s face it.”

Others expressed a need for more information about community events and activities which could improve social integration and support. The need to “to tell them (community members) what’s going on” was emphasised: ‘Cause I can’t come up here and then find out ‘oh, yeah. We’re going out somewhere …’ Participants expressed the need for a calendar of events: “That’s gotta happen, especially … like they have community days and all that. We don’t know what’s going on, do we?” The importance of “getting people tapped in to community events” or “community activities” was emphasised by respondents.

“I think if each community could get together and have what they call a little meeting place…it’s a place where people can go and know that they can voice and feel and say”

3 Need for pride
The importance of building pride in the community and in culture was commented on by a number of respondents “We need to make people proud of who they are, ‘cause some people aren’t”; “(its) about giving them some pride also, and some hope in their lives”

“The influence of the cultural the sense of belonging to place and cultural events and knowing about how our ancestors tackled things in the past, that sense of pride is very strong. That sense of responsibility to community is very strong.”

“You start to look at how far we’ve come in that forty years ... it’s because we’re achievers. But when you look at it in terms of ‘we’re achievers’, then it just puts a more positive focus on the way that, that people can think about themselves and acknowledge that there are these things that have been done. And I think that’s really important.”

Pride in self and community was seen as one way to increase resilience. A couple of respondents mentioned mentoring as a practical strategy to build self-esteem, pride and community capacity: “building their confidence up”; “some people the difference it made, just that they were the peer mentor. ‘Cause all the peer mentors were Aboriginal people. So it was Aboriginal people mentoring Aboriginal people”

A number of respondents were clear about the beneficial impact of role models speaking about depression to reduce stigma and shame: “They’ve just got to get more role models out there to tell people that they’ve had depression.”; “They’ve just got to get more role models out there to tell people that they’ve had depression”; “role models who have the experience of chronic disease or mental health (could be encouraged) to speak out about it.”

“I’m pretty sure that a lot of Aboriginal sports stars, maybe, a couple of them may have had depression just making people aware that no one’s invincible from depression or anxiety or, grief and ... ‘cause everyone’s gonna have to deal with it”
“(we need) community members from the local community to speak out about it so people can see it is possible to have a career in the face of challenges.”

Recognition of the “stacks of unsung heroes” or “deadly heroes” was seen as a way of building community pride. “Barak’s story” had considerable resonance and there was a desire for this to be more widely known: “I think one of the things that we don’t do properly, is the just and proper recognition ... That we give people proper respect.”

4 Need for information

Both community and service providers expressed a need for culturally appropriate, trusted, relevant information in a range of areas including services and entitlements and mental health.

i) Services and entitlements information

Both community and service providers demonstrated a low level of knowledge about readily available services or supports such as mental health plans. Common responses to the provision of information about such services included “that’s the first I knew of that” or “thank you so much for letting me know that” or “that’s really good that you said that, well that’s really good to know.” Improved information about services that addressed this perceived need was required. Many expressed a low level of confidence about community members or their own capacity to navigate the complex systems of healthcare and support: “We need information about services”; “(I need to know) these are the kind of benefits you can access”.

Information was needed about

- Services
- Benefits
- Entitlements
- How to access the health care system
- How to access food vouchers from other services
- Mental health plans
- Concession schemes for people with a chronic illness
- Travel assistance
- Crisis assistance
- Carer support
- Legal advice
- Financial advice
- Disability aids
- Dispute resolution

Participants expressed a desire for written, trusted communication for community members that could be trusted “not just an information day”.

**ii) Mental health information**

Respondents identified a need for more information about mental health. This was identified by both community respondents and service providers. “I think a lot of that (mental health information) needs to go around the communities, going out into communities; making families aware—this is why their loved ones are acting up, this is why” information sessions on mental health and wellbeing were suggested by some “If we started to run, a couple of programs here and there—just where the community come down and get educated (on depression and grief) I reckon that’d be really good.” Such opportunities were seen to provide a venue “where we can, share information and support each other.”

The data showed a clear need for information to reduce the level of “*stigma and shame*” in the community that was associated with having any issues with mental health.

*Information needs included:*

- Mental health
- Mental health first aid
- Anxiety
- Depression
- Grief and loss
- Trauma
- Addiction
A couple of participants expressed a desire for “our own resources (on depression) with our own Victorian Aboriginal faces. Not this stuff coming from Queensland or the Northern Territory. We need our own Victorian Aboriginal resources. That makes the world of difference to our mob, and—local artwork. Something that’s easy to read and bright and colourful.” Others suggested digital information “to go out to families; Not just handouts, but like, DVDs and the digital storytelling” explaining that “a lot of people can’t read and write. A lot of people can’t be bothered reading and writing even though they can.”

iii) Family history information

A number of respondents talked about the importance in healing of having information about their own story and their own family history: “we sort of really need that sense of belonging and knowing of who we are before we can go any further with anything else. Otherwise you lose it or you just don’t know why you’re doing what you’re doing or who you are” The need for access to “family history stuff” included access to “information about family trees, photos past and current and stories past and current”. Such information and resources was seen to help with “belonging” and “connectedness”.

5 Need for someone to care (case management and support)

“People just want someone to care. They just want someone that’ll listen. They just want someone that will take that time.”

“They must have one contact sort of regular and consistently. Someone to yarn to. Someone to, maybe, help them”

Professional support with navigating the systems was seen as vital for people with a chronic disease and depression, anxiety or a related disorder: “navigating the systems; knowing what to ask; knowing whether you’re allowed to ask. It’s empowering people. You have to empower them. That’s a big thing with chronic condition and mental health. You have to, you have to empower them”. This underscored the importance of “just making sure they’ve got maximum access to what is available whether it’s GPs or counsellors or outreach workers from whatever, or drug and alcohol workers.” Other areas where people needed assistance with accessing services or entitlements included “food vouchers, cab charges for specific purposes, appointments with
People wanted “one person who cares... to help with all these things your housing situation; your mental health; your medical appointments”

“(People need) support, I think. Just being able to ring someone if they are having a bit of down time. Just a number that they can ring and just have a yarn. I just think they don’t get enough support for them”

Without assertive and proactive follow up professional support and care Aboriginal people with a chronic disease and depression or anxiety were “falling through the cracks” in the healthcare system: “I got put through to people but they never followed me up, so I’ve been suffering for 12 months. I’ve got to tell you that. Yeah. And I’ve been just laying here. The bones and the joints didn’t work...I suffered for a long time. I’ve basically got forgotten. So 12 months down the track I’m f***ed.”; “I’m six months overdue for my assessment too and it’s my fault, I haven’t been ... but I’m not reminded”; “For a week I was laid up and couldn’t do nothing. And no one come near me.”

Improved care co-ordination was also required to improve outcomes of Aboriginal people with a chronic disease and depression or anxiety:

“It didn’t matter at what point you interceded. So if you went out and fixed all the housing needs up, you still need to have ... you know, the employment needs and income needs looked at and the training and development to generate the income, and so on. So you have to do something and all of those aspects, for the problems to be alleviated .....There’s an imperative to have all those things .., operating together”

“I emailed through to six different service providers to try and get some support... hopefully we’ll sort it out, but these things can take weeks to try and get people to return your call and to chase it up you’ve got to have time, you’ve got to have persistence. You’ve got to have guts”
“She had to get out the very next day because she couldn’t get her lawns mown—and mow her lawns herself the next day after she had major surgery. ...that’s wrong for Elders to have to do that. ... But it was like ‘you’ve just come out of surgery, you shouldn’t be mowing lawns!’”

Assistance with navigating the “bureaucracies and bullshit” of the community care scheme was clearly required by Aboriginal people with a chronic diseases and depression or anxiety: “you’ve got to have workers that are willing to spend the time and the energy. There’s funds out there but you’ve got to have someone that’s gonna do the work to find it”; “I’m applying as well. I’m applying as well. I haven’t been serviced (home help) for nine months. And they say ‘oh yeah. you’ve got to be home to sign the paper’”; “we did get the cleaners to come in ...but I’ve said ‘they can’t come that day ‘cause that’s when we have lots of appointments with doctors and things. Can you make it for a different day?’ And she, yeah, didn’t get back to us. That was half a year ago”

6 Need for Healing

i) Cultural Healing

Increasing access to cultural healing was seen as another important role of the Wurundjeri, in particular access to cultural traditions such as “smokings, done in the traditional way.” Respondents identified “a need to be smoked” and that smoking was important to help people “feel culturally, more well” and important to emotional and social wellbeing.

A number of respondents spoke of the healing power of being “on country”: “the best place for their healing is on country”; “sometimes a whole lot of Elders, go back to the land—or men, with me—go back to the very place where they’ve started off. They come back like new people.”

“You’ve got to look back to history. Like, Aboriginal and Torres Strait Islanders back then didn’t have doctors or anything like that to address mental health. But what they had was their kinship systems. And through the kinship systems they were able to address the women’s business and the men’s business. So,
whenever someone was feeling sad in the community, you have
 ten aunties there who will sit down and yarn with you, help you”

“Spiritual healing” was also identified as important: “I believe we should try and keep some
cultural spirituality in that journey if we can.” It was healing when “we found how we could do
some things that were culturally spiritual for us. Talked to our ancestors and had little nights of
gathering around as a family group and saying good things about each other.”

ii) Counselling
Respondents named a range of issues where mental health support was required but either
unavailable or culturally inappropriate. These included a need for assistance with managing
 trauma, depression, anxiety, self-esteem, drug and alcohol, exposure to violence, family
violence, grief, children’s drug use, carer support and numerous other issues.

iii) Story telling
The need to tell one’s story to help make sense of one’s life was commented on by numerous
respondents: “The communication thing is just huge in relating to each other and relating to
community; that story telling is really important.”

The process of story telling was seen as an important part of the healing journey:

“Pills, pills aren’t gonna touch this stuff. I just find, when they
tell their story ... and they would start telling me stories that was
so therapeutic—just for them to sit. We’d all be howlin’ on the
side of the river—the whole lot of us, including me. ... But that
was almost like a weekly thing. And, and just getting those
stories out. It was amazing Narrative therapy. Where everyone
could just tell their stories”

“It all links up with depression. And if you’re not sorting things
out; you’re not talking to anyone—of course you can’t handle it
in there, so it just explodes in different ways”
“(exploring) who do I hope to have influenced the most’ and that brings up a whole gamut of things because once you start talking about grandchildren or relatives and so forth, people just, and if they’ve had some any positives and they will just open up into another world”

“Sometimes a good yarn-up and a good cry is all I really need”

“I think the most important thing is that you listen to people’s stories and validate what they’ve been through. And help them understand why they, why they might be where they are now. To help make sense of their stories, their life. ‘Cause they may not know and they may hold a lot of guilt and a lot of shame—and just help people understand, that’s it not their fault. That’s helping them identify where all that stuff comes from—so that they’re not, feeling shame. It’s all about that self-worth stuff.”

**iv) Support Groups and Yarning Circles**

Culturally appropriate groups were seen by some to be part of the healing journey, these included therapeutic groups, yarning circles and disease management ‘clubs’; “we know that when we’re in groups we can tend to share more.”

“A lot of people were saying that in the groups stuff, that they’ll share stuff that they wouldn’t share with a counsellor if they feel like they’re in a really safe space. So we know that’s powerful. We know that’s transformational.”

Support groups were seen as important in helping people heal: “So it’s a really great sharing something that they have in common... sharing their stories ... getting our men and our women together just to chat openly...about their lives and what they’ve been through—‘cause a lot of them have been through trauma.”

Support groups focused on the following issues were suggested by respondents:
- Patients with a chronic illness
- Carers of people who are unwell with a mental health issue or cancer
- Families that are affected by substance abuse
- Men’s group
- Grandparents raising grandchildren
- Elder’s group
- Women’s group
- Family circle
- Mum’s support

7 **Need to welcome and be welcomed**

Aboriginal people from ‘out of country’ were identified in the data as having a strong cultural need to “look for my people” and connect with the Wurundjeri community: “even though they’re Wurundjeri they’re still my people”. The need for Wurundjeri “to respectfully acknowledge others from other Country and be welcoming” was seen as very important: “you still have to welcome and acknowledge and respect the country where they’ve come from.” This welcoming was seen as a way for the “traditional owners, Wurundjeri, (to take) responsibility about caring for people and country”
What helps?

Thematic analysis of ‘What helps?’ is presented separately for the service providers’ perspective (Study 1) and the clients’ perspective (Study 2).

‘What Helps?’: Service providers’ perspective

Building community

The importance of social support and strong community connections in assisting patients or consumers to manage the challenges of life was identified by many of the interviewees: “a bigger healer than medicine itself.” In the words of one interviewee “I mean, we all … bloody hell! Whether we’re grandparents; parents—it is just horrendous. And we’re all isolated.”

Interviewees drew clear parallels between health and building social connections: “Connecting with community” was seen as a key part of the client journey to wellbeing:

“We reckon, in our own little quiet way, that we can help contribute towards making people feel stronger and, and healthier just by reducing their isolation—social isolation—and lack of connectedness.”

“Through connectedness...you can see the people getting well. You know, and then they start turning up at programs and turning up at community events, and then they usually start contributing back.”

One interviewee observed that there was a lack of awareness of community events in the broader community which made it difficult for people to reconnect with community “there really is not too many opportunities for people who do wanna sort of, maybe, come back into the community. Or, you know, get out of the house and do something. What are ... what are you gonna do? Where are you gonna go?”

Building informal social networks or “connectedness” was also seen as a way to improve wellbeing through ‘connecting with others’: “sometimes they live alone; they could be totally
isolated ... and it’s really good to have that connection to hear how other people with the same diagnosis are travelling. Share ideas, opinions ...”

Enhancing connectedness was seen as one way to overcome “the impact of lateral violence in our community, we know that people ... they opt out, they don’t go to community events....(we need people to) get reconnected and feel stronger within who they are.”

**Connecting with culture**

**Connection with culture** was seen by many to be a very important part of healing: “We have to get back to the way we culturally healed, how we culturally manage things. I mean, these are all things that were occurring in our cultures and through our ancestors, and how did they deal with it?! Go back and have a think!”

“When Aboriginal people are allowed and have the freedom to express their culture, and that can be in their dancing, their art work, any form where they’re allowed to be creative...being given the freedom to express ourselves in country with whom we like to associate with that’s (when) people flourish.”

**Art and traditional crafts** were seen by some as an essential part of healing and to be an important way to build community engagement: “one of the big things for mental health is that doing art. Art’s good for everything.” This included learning “traditional things, arts and crafts, basket weaving, boomerangs, painting”

**Information about mental health**

Interviewees were clear that their needed to be more information ‘out there’ on mental health matters:

“Just trying to make people, more people aware of what it (depression or anxiety) actually is, I think, would be, like, the best way of going about it... ‘cause I don’t think people actually know what it is, and people have probably experienced it and not thought that it was it.”
Reducing stigma and shame: Normalisation

Interviewees also emphasised the need for targeted approaches for Aboriginal people to reduce shame and stigma associated with having mental health problems:

“I think they just need more programs about stuff. Like mental health and, depression and ... they’ve got to really target them. I don’t think they’re really targeting them, ‘cause it’s just thrown in there with the other stuff—and it’s not really getting looked at like it should be.... Just to make people more aware that it’s not a bad thing. That’s what I reckon the big, big picture is with Aboriginals—it’s that shame.”

“I think, ‘cause it’s got that sort of stigma about it. Like, you’re mentally, you’re mentally not there or it’s a shame factor. ...Just, like, trying to make people more aware about the mental illness, and it’s not a bad thing. It’s, you know, it’s just what happens for some people. I think people’s perception of it is, like, they just think it’s ... anything to do with mental, they’re ... they’re f***ed in the head, more or less. You know, like they’re ... they’re not there.”

“I would say to them, most probably what they’re feeling is normal.......normalise it instead of making out, you know, they’ve got a illness or something like that. Normalise it and say that ‘you know, what you’re feeling is, is normal’”

Telling my story

Numerous interviewees emphasised the therapeutic benefit for people with a chronic disease and depression or anxiety of being able to tell their own story: “the communication thing is just huge in relating to each other and relating to community; that story telling is really, really important.” One interviewee discussed the importance of helping people who may have a life threatening illness to tell their story in order “to leave something for their loved ones.”
benefits of giving people the opportunity to tell their story and reflect on their life were manifold:

“Talking to people, getting their stories and it’s just one big, sad thing. ‘Cause, you know, we’re carrying the hurts of our people. We’re carrying it. And sometimes it gets so heavy ...that you can’t cope”

“just getting those stories out. You know? It was amazing. Narrative therapy. Where everyone could just tell their stories and it’s amazing.”

“The most important thing is that you listen to people’s stories.... and validate what they’ve been through. And it sometimes help them understand why they might be where they are now. To help ah, make sense of their, their stories, their life. ‘Cause they may not know and they may hold a lot of guilt and a lot of shame—and just help people understand um, that’s it not their fault”

“I’d really love to see some community spirit together and ...just have some really good yarn-ups about it. Sometimes a good yarn-up and a good cry is all I really need......I think if each community could get together and have what they call a little meeting place, it can be sorrow time, sorrow place, whatever. But it’s a place where people can go and know that they can voice and feel and say, you know say ‘I just feel shithouse about it all today. I don’t know what to do’. Just let people voice, because often we’re suppressing it”

**Building pride**
The importance of building pride in community and history was reinforced by interviewees: “just that recognition and respect can make so much, much of a difference. ...... It is, really important, I guess, for us.”

“When you look at it in terms of ‘we’re achievers’, then it just puts a more positive focus on the way that, that people can think about themselves and acknowledge that there are these things that have been done. And I think that’s really important.”

“We got so many deadly heroes in our history. When you look at it, you think about the things that people did. I watched that ‘First Australians’ and I saw Barak’s story there, and I thought ‘well, look at this.’ A man at odds with the system in many ways, and in many ways with the world. The people that were there, you know—in our history—that have got up and fought............. And I think one of the things that we don’t do properly, is, the just and proper recognition,....that we give people proper respect.”

A number of interviews suggested that the community needed “role models” of well-known Aboriginal people “who have the experience of chronic disease or mental health to speak out about it.” It was also suggested that “role models” could be “community members from the local community who speak out about it (chronic disease and mental health) so people can see it is possible to have a career in the face of challenges.”

“They’ve just got to get more role models out there to tell people that they’ve had (depression). Like, ‘cause I’m pretty sure that a lot of Aboriginal sports stars, maybe, a couple of them may have had depression. Just making people aware that no one’s invincible from depression or anxiety or , grief and ... ‘cause everyone’s gonna have to deal with it.”

Holistic focus
Some interviewees were aware that health professionals working with people who have a chronic disease rarely addressed mental health issues:

“*It’s that whole holistic thing. Sometimes people wouldn’t even be aware that they have the ... the depression and anxiety along with that chronic disease*”

“It may not just be the one disease in isolation that you’re looking at. And I guess that comes back to the whole mental health, you know, social and emotional wellbeing”

“I think it’s (mental and physical health) treated as two different things where it should be combined as one, you get told that you’ve got this chronic illness and that’s what you’re treated for. And then, all of a sudden, you get depressed—‘oh well, we’ll put you on a mental health plan now’. But it’s never combined together or ...never discussed or put in the right practice or place as far as I’m concerned. “

“I don’t really feel like mental health has been focused on that much, to be honest....I guess because you can’t see it. Like, you can’t see the physical effects because they’ve already got all of these other diseases and complications to sort of deal with.”

**Support groups**

Some interviewees strongly emphasised the benefits that people got from participating in a well-run, therapeutic and culturally appropriate group:

“No one Aboriginal person’s the same as the next, most certainly. And the one common thing is you’re more likely to have a range of similar, similar traumatic events happen and be impacted by tragedy or actual trauma... When we’re in groups, we can tend to share more...(people) share stuff that they wouldn’t share with a (non-Indigenous) counsellor, if they feel
like they’re in a really safe space. So we know that’s powerful.
We know that’s transformational... when they share their
stories and they realise that they’re not alone.”

Disease management groups or clubs were also seen to be a beneficial way to promote sharing through “all these little conversations, (Aboriginal people) talking about their problems to each other”; “when they can talk to someone else about their same condition, it’s that much easier.” This was also seen to assist in reducing stigma and shame; “There was shame, yeah, in the community. and everyone was suffering in silence because a lot of people didn’t want no one else to know that they had it or they were managing it”; “I notice ... when the community are involved with each other, —depending on what health condition they’ve got—even just sociably ... life’s a lot better for them”.

Belonging

Many of the interviewees reinforced the importance of “seeing an Aboriginal face”: “it’s about, coming to ...somebody who they can relate to”. At other times it is about being able to deal with issues “in the cultural way”. One interviewee explained the supportive role that they play with clients “they feel that I’m their safety, their bodyguard—someone they can feel safe around.”

What was important was seen as “just making sure that they know they’re not on their own. I think that’s the most important thing.”

Yarning

‘Yarning’ was seen as vitally important in helping people to manage the challenges of having a chronic disease and depression or anxiety: “it might be somebody just sitting down and yarning to them, just visiting, just presencing, being beside them...calming them down” ...”people want to see... that it’s a relationship and you’re just yarning”

“I reckon getting alongside them, but not being judgmental—being a friend to them. ‘Cause people just close up if you’re just there to investigate what problems they got, just getting alongside of them, being their friend...And being interested in them. And then helping them with their chronic stuff”
“We’ll go through, like we’ll have a whole discussion about you know what you can do (about management of depression) and at the end of it like I always say, ‘you know where to find me and we can have a yarn,’ and stuff like that.”

“The way to kind of communicate in a positive way with Aboriginal and Torres Strait Islanders is through yarning. Like, we all said that having a yarn is far more important than just sitting down and you throwing me questions and, y’know, answering the questions and then just having a conversation that way”

Counselling

Interviewees expressed mixed feelings on the role of counselling:

“They see counselling as ...people have “a problem” and they help people work through “the problem”, or “the event” and that they’re going to come out the other side well. But a lot of the people that I have contact with, they’re never going to come out the other side of their anxieties and traumas and depression. All you (are) going to do is hopefully help them manage it a bit better or perhaps feel less guilty about it.”

“We work on one problem at a time, not all at once, ‘cause you’re not going to do it all at once. It takes time. Sometimes it takes years if the depression has been there for so long. You know, it takes time to have this growth and move on and find out where you need to go and how to, how to put things into place to prevent it from coming back; how to process it and put it in the right place”.

While counselling and teaching psychological strategies to manage mental health issues was seen as vitally important, the challenge appeared to be getting the right support: “I always
encourage counselling and a good GP because it’s often a good GP who will keep people going. And they’re the best ones to assess whether or not counselling or medications needed.”

Mental health nurses were seen by some as providing an model of support that was better suited to the Aboriginal clients:

“Now I’m referring more to mental health nurses. I think they’re actually better suited to quite a few of the (Aboriginal) clients I’ve got because they don’t think they’re going to help somebody solve their problems they’re just going to help them manage it and make sure they’ve got the best medications. Manage it best you can. Sometimes that’s more appropriate to me than a white middle class sort of model of counselling.”

**Intense support**

Overall interviewees were aware of the complexity of the issues surrounding Aboriginal health and the connections between chronic illness, trauma, social and emotional wellbeing, depression, economic, social, financial, relationship and housing needs amongst others. The interviewees saw their job as providing intense support and proactive engagement and advocacy to improve long term outcomes for clients, their family, carers and community. There was no quick fix to the generations of need that have led to the current experience of Aboriginal people with a chronic disease and anxiety, depression or related disorders.

“Aboriginal health is about holistic health. It’s a number of things. It’s not just their condition. It’s their housing; it’s their employment; it’s their housing; it’s their children; it’s their, family; it’s ... all these other different things that are going on in their lives. So they need the support of organisations; they need to get patterns—changed behavioural patterns. That needs to be supported. They need to know that they are supported. They need intense support to begin with.... Because what happened today, for instance, in their lives, might change things for what’s planned for them tomorrow. Within 24 hours lots of things change for a
person with a chronic condition and a mental health issue. What was a priority yesterday is not today, you know.”

“You’ve gotta pursue them; and you’ve gotta try and pick them up; and you’ve gotta try and find a way ... find something that’ll get them out of that haze—something that’ll make them want to struggle to find an answer... ...I chase them and I talk to them and I spend time with them. And that way I get to know them and I get to find out what it is that would help them....... and so, I find some little chink in their armour that’s enough that’ll pull them out of it”

“But, how we handle it—because we pump, pump, pump ... just re-engage. It’s about that constant contact all the time, Knowing your clients ... who they are ...knowing who, who’s gonna possibly end up that way and keep at them. Like, we’ll make phone calls continually or you visit. Knock on the door. Send someone out. Knock on the door, Because, I think it’s most important is that we show that we care about them”
‘What helps?’: Clients’ Perspective

Connecting with community

Community members were aware of the importance of social support: “If I get out and about the tension goes a little bit.” Having a “good network” was seen as an antidote for depression: “the number one thing to help is connection, and belonging to something.” Community members acknowledged the importance of “someone for them to talk to” or “more people talking to them” and “catching up with all these people that you haven’t seen”. Community members wanted the opportunity to “have a little chin wag about things”.

Friendship and support from other Aboriginal people was valued:

“I guess the big thing is them being Aboriginal. So, they understand. You know, if you’re an Aboriginal person there’s so much about your life that is, you know, idiosyncratic to being Aboriginal. And if you say to someone who isn’t, they don’t get it. They just don’t understand.”

“This is my community for the rest of my life.”

Some wanted more community events to help people connect “More barbeques so people will get together. ‘cause they get to talk more when they’re all together, I’ve noticed.”

Others simply wanted to know what was happening in the community; “no one knows what’s going on!”, “like they have community days and all that. We don’t know what’s going on, do we?” A desire for access to information regarding the events that were held in the community was clearly expressed by a number of community members: “(you need to) tell them what’s going on. (the) events. ‘Cause I can’t come up here and then find out ‘oh, yeah. We’re going out somewhere.’”, “(someone needs to) send out a sheet with the events that are on.”

For others access to groups was seen as a way to connect “programs that people can participate in. women’s group, men’s group, parents groups, craft groups, sporting groups” as well as “Elders group” Benefits included “meeting other people and I’m away from the fighting and
Some wanted less structured social support groups: “maybe at the beach—a barbeque at the beach, or parks and gardens”

Community connection was seen as vital in terms of mental health for those who were off Country:

“It’s like when I first came. I was lost. I moved down here last year I didn’t have my people. And I came here, and everyone’s just so good. You know? I’m home. It was just so alone. I had people to talk to, but...(I’d) lost heart.”

These benefits of connecting were also passed down to the children “And then I come here and, interacted with community and it’s just been ... my kids are much better, they’re interacting.”

Connecting with culture

Connection to culture was viewed as a vital part of healing: “We are nothing. If that is gone I am just a shell”- “I have a story”.

“We like doing a lot of cultural things ‘cause a lot of us didn’t even know we were Aboriginal until we were a bit older and we don’t have that culture. And it’s learning that and creating that sense of community is really— It’s part of the healing. It’s made a big difference like that.”

Information on services/supports

Community members expressed a need for information on a range of topics: “You’ve got to know. You’ve got to know what’s there.”; “Just don’t keep on ... just don’t keep things to themselves and that. The community people have to know”; “I’m surprised they don’t tell you
what they provide or anything”; “look, I don’t know what goes on or not. You’ve got to tell me what’s available”

“I didn’t know that these services were provided, because you don’t know these sort of things and you’re not told anything so it’s sort of difficult to sort out what you might be eligible for”

There was a real gap between those with knowledge and those without: “that’s just it. You’ve got the knowledge. If you don’t have the knowledge…”

Palliative care was an area that people needed more information on:

“We should know about palliative care and all those sort of things. It’s just very important. When people are in hospital they need the support.”

“I think we should be taught about palliative care to help everybody, anywhere. So that they know about the service, and that they don’t have to do it by themselves.”

Improved communication regarding services and benefits was desired by some respondents “we need a newsletter and that newsletter would have: ‘these are the kind of benefits you can access through … these are the kinds things you can access through the health service”

Information and support for access required for:

- Palliative care
- Subsidised transport to medical appointments - taxi scheme
- Disability parking
- Grief support
- Home help
- Lawn mowing services
- Support services
- Respite care
- Counselling services
• HACC services
• Community supports
• Allied health

**Telling my story**

Being listened to was also important with a number of respondents expressing a wish to tell their story: “I’ve been thinking about it. I need the book of life (to tell my story). ‘Cause I’ve got it from a young age, and it’s all there.”

**Access to trusted medical care**

Finding the right medical care was a challenge for many. It was important to community members that a doctor “spend more time with their clients” or “sit and listen to you” It was also seen as important that medical staff “know the community and have got a better understanding of the community and stuff and know what they’re doing.” Relationship and true connection was highly valued: “cause any doctor can go ‘hey, how are you going? Yes, no. See you later’, whereas an actual doctor will sit there and have a conversation.”

Community members described the features of their relationship with their doctor that made them feel like their health was valued and that they were valued as a person:

“Sometimes you’re in there for half an hour ‘cause the doctor makes you feel important. Asks you what’s wrong; and then writes down everything what’s wrong; and then looks into everything—all your history on what’s wrong and stuff like that. … all your history on everything that is wrong with you. So by the time … next time you come and see them, the doctor more or less knows exactly what’s wrong with you and how to pinpoint how to give you the right medication and everything. The doctor also gives you information about it too, so you understand it better. That’s what I like. They are very, very thorough and very welcoming.”
“you’re comfortable with the person. When you actually feel like a human being after you’ve spoken to them”

Having to relate to many different doctors within a medical service was a challenge for some:

“It’s good to go to the service if there’s one doctor, but when they keep changing them, you don’t feel comfortable because you’ve got to keep explaining yourself over and over again. And that’s what I don’t like. Starting from scratch all over again. And you just get sick of doing it.”

Changing doctors when they had left a practice or medical centre was difficult with new doctors regarded with trepidation: “the doctor’s left., gone … was a really good doctor and, yeah, I don’t know who’s there now They were was the only one that was listening when he said about all his problems”

Many found sympathetic doctors through word of mouth: “the doctor left so we decided we’d go … to see this other doctor…she introduced me to them because she said to me ‘they’re kind and that there’” Others were referred to specific doctors by service providers: “‘Cause if they weren’t there I wouldn’t be at my doctor. I’d be still undiagnosed and bouncing off the walls. Yeah. Because, her choice of … yeah, their choice of doctors is brilliant.”

Some community members reported enormous lack of cultural safety when seeking medical care “They were so incredibly rude. I was just shocked. She actually sat down and worked out what percentage Aboriginal I was. I am deadly, deadly, deadly serious…all I could say to her was ‘well, I’ve never thought about assessing what percentage I am’. I said ‘I don’t think of myself as being a percentage.”

Past traumas were hampering health service utilization and so impacting on chronic disease outcomes “some of them are scared when they go to the hospitals …because they’ve grown up in institutions and that, and the way they’ve been treated and everything—they get scared when they come into government places and all this sort of thing”
**Someone who cares and follows up**

A number reported on the issue of not being followed up proactively which led to them waiting for follow up, assuming it was coming at some stage and so falling between the healthcare gaps: “12 months down the track I’m f***ed (after no follow up).”

This need for proactive case management and care coordination was evident across respondents. “There’s sort of no one person who’s helping you manage all that stuff”; “(It would be great) if you can have someone that can follow things up for people”

“There’s no follow-up much. I just got crook and ...they didn’t help. They didn’t help. Yeah, I did say that I wasn’t well, but no one helped me.”

Community members struggled to navigate complex health systems to get the care they needed. There did not seem to be shared understanding between the community and the mainstream system as to the role of the health professional in following up and booking appointments:

“I’ve pulled myself out of the gutter. Well, I went to (mainstream service) I didn’t really feel like they didn’t want to act, I just had to act by myself. And I couldn’t. I’m not happy. I’m not well. I’ve pulled myself out of the shit. But it’s all there.”

Navigating the bureaucracies of health was a struggle for many:

“I’ve gone through the bureaucracies and bullshit. It just got lost. Yep. They left me for 12 months.”

“Hopefully we’ll sort it out, ... these things can take weeks to try and get people to return your call and to chase it up and you’ve got to have time, you’ve got to have persistence. You’ve got to have guts, because it could be ... they can be really quite rude when you ring ...”
“if you can’t get anyone there, you go to the department. You have to go to the funding body…. but you need a service provider that is going follow it up and follow it through”

“It’s hard though, because you’ve got to have workers that are willing to spend the time and the energy. And “it’s very hard to find workers that are willing to. There’s funds out there but you’ve got to have someone that’s gonna do the work to find it.”

Navigating the politics of health was also an enormous challenge. Disparities in access to health service were reported based on who was known or what family group they belonged to:

“like in every community. If you ain’t got the right family name, you don’t get in nowhere …it’s bullshit!”

“They should be looking out for the whole community. age or family or tribe or whatever. …it’s the whole community. It doesn’t matter where you’re from or who you are or what, you know, what family you belong to. It doesn’t make no bloody difference.”

“I’ve been ringing for my mum, to take her to the hospital or whatever. They don’t come there ‘til an hour later. Or they don’t show up at all. And that’s what I mean. Like, if they only help who they want to help … like their own family. But if you’re not their family or blood, they are not gonna help ya.”

“They need to feel like they’re treated fairly. there’s lots and lots of issues …people don’t feel like it’s being fair. Like, ‘you get this help, but I don’t get it’”

Lack of clarity regarding responsibility for follow up led to very ill people falling through the gaps:
“She doesn’t follow, and she doesn’t push. ’Cause, see, I’m six months overdue for my assessment too, and it’s my fault, I haven’t been ... but I’m not reminded.”

“They’ve got these jobs, you know? They’re working for the professional people and that but I had to ring up myself to book by own f***en’ bookings. Look at me. I’m f***ed.”

“I never got any help. and I got put through to people but they never followed me up, so I’ve been suffering for 12 months The bones and the joints didn’t work...so I suffered for a long time. I’ve basically got forgotten”

“Like I said, I have to do everything myself. And I don’t mind it but I think about all the others”

“I went to a doctor today. Because, to be honest, with my particular illness, I’m meant to have three-monthly tests, and I haven’t had one in over 12 months. It’s probably, to be honest, more like two years, but I’m a bit embarrassed to say that.”

**Access to community services**

Negotiation of the assessment process and access to community services to support in-home care was also a challenge for some especially for services after hospital discharge “when I had the varicose vein taken out of my leg. For a week I was laid up and couldn’t do nothing. And no one come near me.” “it was like ‘you’ve just come out of surgery, you shouldn’t be mowing lawns!’ and She said ‘I can’t lay here looking at these lawns being like this’ ”

There was also communication issues regarding sustaining services that have been allocated: “we did get the cleaners to come in ...but I’ve said ‘they can’t come that day ‘cause that’s when we have lots of appointments with doctors and things. Can you make it for a different day?’ And she, yeah, didn’t get back to us. That was half a year ago”; “I haven’t been serviced for nine months and they say ‘oh yeah. you’ve got to be home to sign the paper.”
There was general agreement that professional mental health support in the form of counselling was useful and important. “I think that counselling is gonna help.” Some of those who had been through counselling spoke highly of the process: “if it wasn’t for my psychologist and my counsellor giving me the insight on how to cope with it ...I’ve kept that with me all through my life. Like ... so all these things come back and I go ‘nah. Ok. I’ve got to deal with this. I’ve got to deal with it”

In particular grief counselling was seen as important: “So many of us ... So many relatives and that passing on. So they need that support sort of thing”; “even after their loved one dies, just getting them in the right direction of counsellors and that would be a good idea.”

“I went to see a counsellor. Really good. ... I don’t know. I just needed help. I knew that. I knew that I needed the support ...she got me into counselling. ...that really helped me. ... We talked about grief and that. Just about grief. I talked about what I wanted to talk about.”

The importance of maintaining a relationship with a counselor who could be trusted and who would be there for the long run was emphasized. In particular this allowed people to reduce re-traumatising through the constant retelling of traumatic life events:

“I won’t see no one else because they know me. I don’t have to explain all the bulls**t again to them. Because what they don’t realise is when you ... when you’re going in to somewhere and you’ve got to explain it again, then ...resurfacing. Then ... you’re bringing up your past and then you’re going through all the trauma again, when you just don’t want to do that. You want to leave it there.”

The retelling of story was seen as harmful and painful. Respondents expressed a wish for people to “read the notes” or “get it (the story) off the last person, read it, then you’ll understand where I’m coming from.” In particular respondents did not like “pushing and pressuring—’cause that’s
when we do lose the interest and say, ‘well f*** ya!’”. In addition, the issue of old traumas resurfacing also led to a need for counselling: “(I need counselling) as being older. ‘Cause I dealt with (earlier) but I’m older now.”

Some reported poor experiences with counselors particularly in terms of cultural understanding and safety:

“I was seeing a counsellor but, she was good and that, but it was just weird ‘cause she wasn’t an Aboriginal or nothin’. She sort of, yeah ... I sort of felt like it wasn’t really helping at all.”

“I went (to counselling) and seen ... one of them people, ...I only went the once. It’s a waste of time.”

“I suffered depression for a long time, on and off all my life I’ve been having different psychologists, different counsellors ... Never found one that was suitable.”

Well, they put me into counselling. I went probably three or four times. And each time I was repeating myself to the same woman. I was repeating myself ... and in the end I said to her ‘why am I doing this?’ In the end it was doing my head in. So I said ‘I’m over it. I’m finished. You can get your money. I’ll get the money refunded back’. And I finished. I can’t do it no more. And I haven’t found a counsellor since.”

You’ve got to have the support behind you. And if you don’t trust that support, then you’ve got nothing—you feel like you’ve got nothing.

Drug abuse was seen as a way of managing a lifetime of trauma “I put myself through 35 years of drug abuse because of my past, and the drugs were subsiding all my pain.”

Pain management appeared to be poorly handled with an evident need for culturally sensitive pain management services. Issues with access to addictive prescription drugs dependence
issues arose as a source of conflict between the community respondents and medical clinics: “He said ‘this is all we’re giving to you’. And I said ‘no’. And he goes well, you know where the rehab clinic is’, and told me to leave his surgery ‘cause he thought I was a junkie.”; “I’ve been treated like a bloody criminal and I’m not.”

“Not only are you in pain, but you’ve got to put yourself through more pain to get pain management. Like, the stuff I went through not only physically, but emotionally being looked at as someone ... like, a junkie and that ... especially when I’m highly respected That’s the thing, if you get prescribed a medication that’s working for your pain, and the ... for some reason or another the doctor leaves or something. And you go to another doctor and say ‘ok. Well, this is what I want. Can I have that again?’ You do get looked down ... down their nose at you.”

“They said ‘we don’t prescribe drugs of addiction’. And I said ‘darl, I had this happen three years ago. Then this, this and this ...’ You know? Plus, I’ve got a chronic shoulder ... right? Hello?! And they turned around and said ‘no, we’ll send you for swimming in hot water and an aspirin a day’. And I went ‘oh, piss off”

“I’m just looking for painkillers every hour, every two hours, because I don’t like when I’m in these moods and stuff like that. When I’m crabby.”

Doctor shopping to access endogenous opiates to manage pain was openly discussed: “when I went back, they ... I went from 240 (tablets) a month ...she said she was only permitted by the directors to prescribe me 60 a month. then I went to another doctor and told them um, what the d******s down here had said, and she said ‘I’ll get you scripts.’ That’s the way I was doing it”
Alcohol abuse was commonly mentioned as impacting on chronic disease outcomes: “I drank two bottles of vodka in about 12 hours and I ended up in the hospital—and that’s why I’ve got kidney problems and my pancreas and that. Yeah. That was my stupid, dumb fault.”.

For some, diagnosis of a chronic illness led to support for the management of alcohol issues with the irony of now having to take drugs to manage the chronic illness: “I wasn’t on drugs until I went to rehab. Got out of rehab and I’m taking 15 tablets, 18 tablets a day and finding out that you’ve got all these health problems. And I only went to rehab because I had a mild heart attack. And I was still off my head, and I didn’t give two hoots. But when I went to the doctor, he said ‘well, if you don’t stop doing what you’re doing you won’t see Christmas’.”
Possible initiatives to address the identified needs of the community

In the previous section we presented a summary of ‘what helps’ based on the perspective of both the service providers and the client group. In this section we propose a set of possible initiatives which are built on the suggestions of ‘what helps’.

How these initiatives arose.

Based on the identified needs and suggestions of ‘what helps’, the project team proposed a list of ‘possible initiatives’ that might address the needs of the community. These were presented to the Steering Committee and were discussed in Consultations with Elders and community members in an attempt to build consensus regarding these initiatives.

First order initiatives

The first order initiatives were proposed to address the over-arching needs of the community – the needs for connection, healing and information. The two key initiatives at this broad level are:

   vii) the development of a website for the Wurundjeri Community
   viii) the establishment of a Wellbeing Centre for the Wurundjeri Community

Second order initiatives

The second order initiatives were proposed to address the more specific needs of the community – namely the needs for story telling opportunities, building pride within the community, information about services, access to trusted medical care and navigation through the service system, and the need for the traditional Wurundjeri owners to welcome others onto their land. The four key initiatives at this lower level are:

   ix) Case management support
   x) Digital story-telling
   xi) Community Services Card
These six key initiatives are listed below.

<table>
<thead>
<tr>
<th>FIRST ORDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>WURUNDJERI COMMUNITY WEBSITE</td>
</tr>
<tr>
<td>WURUNDJERI WELLBEING CENTRE</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SECOND ORDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>CASE MANAGEMENT SERVICES</td>
</tr>
<tr>
<td>DIGITAL STORIES</td>
</tr>
<tr>
<td>COMMUNITY SERVICES CARD</td>
</tr>
<tr>
<td>WELCOME TO COUNTRYPACK</td>
</tr>
</tbody>
</table>

The table presented on page 100 provides an overview of how the proposed initiatives are linked to and based on the suggestions of ‘what helps’ identified in Phase 1 of the project.

- The left hand column of the table lists each of the ‘things that help’ proposed by the service providers and clients who participated in Phase 1 of the project. A tick is shown to indicate suggestions made by each group.

- The top row on the right hand side of the table lists each of the initiatives proposed to address the needs of the community. These are broken down into the two ‘higher order’ initiatives, and the four ‘lower order’ initiatives.

- Shading is used to make the connection between the suggestions of ‘what helps’ and the proposed initiatives.
  - For example, the proposal of a Wurundjeri Website is based on the suggestions of connecting with community, building pride, and access to and provision of information. The proposal of a Wurundjeri Wellbeing Centre is based on the suggestions of connecting with culture, connecting with community, opportunities to heal, storytelling opportunities, yearning circles, building pride, access to and provision of information, and access to and provision of services. Indeed, the Wurundjeri Wellbeing Centre is highlighted as an initiative that
addresses a wide range of needs of the community, and should be seen as a key priority for the community.

- The four second order initiatives – case management, digital stories, the community services card, and the Welcome to Country Pack – each address two or three of the identified needs of the community.

The diagram presented on the page that follows the table presents a diagrammatic representation of the higher order and lower order initiatives proposed. The diagram demonstrates the inter-relationships between each of the initiatives.

**Implementation of the proposed initiatives**

Each of the proposed initiatives is at a different stage in its development and implementation.

- One of the proposed initiatives has already been developed and implemented. In particular, the Community Services Card was developed by the Project Team during the duration of the current project. A PDF of the services card is presented in Appendix VIII.

- Several of the proposed initiatives are currently underway. In particular, progress has been made in facilitating the development of the Wurundjeri Website, the implementation of digital storytelling for members of the Wurundjeri Community, and the development, implementation and evaluation of the Welcome to Country Pack.

- Some of the proposed initiatives are yet to be developed, namely the Wurundjeri Wellbeing Centre and the Case management model.

Development and implementation of the proposed initiatives is a huge undertaking which will inevitably continue well beyond the life of the current project.

Each of the proposed initiatives is outlined in detail in the following section of this report.
<table>
<thead>
<tr>
<th>Things that help</th>
<th>Suggested by:</th>
<th>Possible initiative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Service Providers</td>
<td>Clients</td>
</tr>
<tr>
<td></td>
<td>Wurundjeri Community Website</td>
<td>Wurundjeri Wellbeing Centre</td>
</tr>
<tr>
<td>Connecting with culture</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Connecting with community</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Opportunities for healing</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Storytelling opportunities</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Yarning circles</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Building pride</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Access to &amp; provision of information</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Mental health information</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Services and supports</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Access to &amp; provision of services</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Trusted medical care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone who cares</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Community services</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Support groups</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Counselling</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Intense support</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>
Meeting the needs: Diagrammatic Perspective
WURUNDJERI COMMUNITY WEBSITE

Purpose:
To inform, refer and connect Wurundjeri community and others.

Project Aims

- To increase the visibility of the Wurundjeri Land and Tribal Council
- To increase connection of Wurundjeri community with key stakeholders
- To increase visibility of the Wellbeing events and the Wellbeing team.
- To provide Wurundjeri community and others with information and resources
- To provide information about services
- To provide information about community events
- To foster a supportive online community
- To increase knowledge of traditions/ family history and culture

Target group
Melbourne-based Aboriginal people with chronic disease who are experiencing depression along with the broader Wurundjeri community.

Key needs addressed

- Need for connection with community/culture
- Need for Information
- Need for pride
- Need for role models
Key strategies

Gain sponsorship for website

Establish a Wellbeing Website

- Calendar of community and external events
- Updates on community news and events
- Links to information about services/groups/programs
- Role models (first Australians, Barak)
- Links to resources /information / quotes re mental health and wellbeing
- Links to the Wellbeing team
- Information on cultural artefacts /history

Establish a Wellbeing Facebook page

- Links to the Wellbeing team
- Calendar alerts / Community news and events
- Health information and events
- Moderated blog / online support

Evaluation

Monitor usage of the Wurundjeri Website and periodically assess satisfaction with the information and links provided through the website.
WURUNDJERI WELLBEING CENTRE

Purpose:
To connect the Wurundjeri community and provide culturally-appropriate opportunities for healing, cultural connection, yarning, storytelling, information-sharing, care coordination and support in accessing services and supports

Project Aims

- To increase connection within the Wurundjeri community
- To provide a culturally-appropriate and safe centre for community members
- To provide healing opportunities to the Wurundjeri community
- To provide the Wurundjeri community with information and resources
- To provide the Wurundjeri community with care coordination
- To provide the Wurundjeri community with storytelling opportunities
- To provide the Wurundjeri community with yarning opportunities

Target group
Melbourne-based Aboriginal people with chronic disease who are experiencing depression along with the broader Wurundjeri community.

Key needs addressed

- Need for connection with community/culture
- Need for healing
- Need for Information
- Need for care coordination
Key strategies

Gain sponsorship for the establishment of a Wurundjeri Wellbeing Centre

Identify an appropriate location and venue for the Centre

Establish the Wurundjeri Wellbeing Centre

Establish and appoint a ‘Wellbeing Team’ comprising:

a) a culturally-appropriate person to manage the Centre to:

- manage the overall running of the Centre
- manage care-coordination
- oversee the development of a program of culturally appropriate healing opportunities, including yarning circles, story telling opportunities, support groups, and cultural activities
- facilitate the various healing opportunities
- identify culturally appropriate information about services and supports for mental health and wellbeing, including counselling and intense support

b) other staff (possibly one or two) to:

- develop a calendar of culturally appropriate healing opportunities
- assist with facilitating the various healing opportunities
- assist with sourcing culturally appropriate information about services and supports for mental health and wellbeing
- assist with care coordination

Evaluation

Monitor attendances at and satisfaction with the various healing opportunities and other initiatives provided through the Wellbeing Centre
CARE COORDINATION PILOT PROJECT

Purpose:

To facilitate community members access to care coordination through referral from Elders and wellbeing team

Aims

- To improve access to health care services
- To increase access to wellbeing services
- To reduce stress on wellbeing team by provision of a referral portal

To increase awareness and understanding of community supports and services to improve wellbeing

Target group for pilot

Wurundjeri community Elders and community member

Key needs addressed

<table>
<thead>
<tr>
<th>Need for Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for Case Management</td>
</tr>
<tr>
<td>Need for access to services</td>
</tr>
<tr>
<td>Need for appropriate mental health support/counselling</td>
</tr>
<tr>
<td>Need for intensive support</td>
</tr>
</tbody>
</table>
Key strategies

- Contact Management team of 2-3 Medicare Locals
- Meet with Care Coordination and Supplementary Services team
- Explore opportunities for improving community access to care coordination services
- Explore opportunities for partnership
- Create opportunities for two way learning between Wellbeing team and care coordinator

Evaluation

- Wellbeing team to record number of referrals
**DIGITAL STORIES (NARRATIVE HISTORY) PROJECT**

**Purpose**
To be heard, healing, to share and pass on stories both now and for future generations. To potentially provide content for the website and or a DVD at some point in the future (pending storyteller consent).

**Aims**
- To enable traditional owners to share and understand their own story
- To increase connection within community by story sharing
- To increase connection with culture/ history and community
- To enable exploration of strength and resilience
- To record memories for future generations

**Target group**
Wurundjeri community Elders and community members

**Key needs addressed**

<table>
<thead>
<tr>
<th>Need for connection with community/culture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for role models/mentors</td>
</tr>
<tr>
<td>Need to tell story</td>
</tr>
<tr>
<td>Need to share story</td>
</tr>
<tr>
<td>Need to understand self</td>
</tr>
</tbody>
</table>

110
Key strategies

- Liaise with Koori Heritage trust and other organisations to support project
- Parameters/prompts for story developed by Research Team
- Invite Elders and community members to participate.....

Evaluation

One or two questions to the story teller about whether the process was a) interesting b) enjoyable c) beneficial and if so in what way?
COMMUNITY SERVICES CARD

Purpose
To inform the Wurundjeri community about available services and supports to support mental health and wellbeing

Project Aims

- To increase awareness of key services that provide support for mental health and wellbeing
- To have this information available on a single resource for ease of use
- To increase the acceptability of utilising available services and supports for mental health

Target group
Melbourne-based Aboriginal people with chronic disease who are experiencing depression along with the broader Wurundjeri community.

Key needs addressed

- Need for information
- Need for healing
- Access to professional mental health services
- Access to trusted medical care

Key strategies
Card Development and community consultation Already undertaken (Appendix VIII):
• Compile a list of key services for mental health and wellbeing
• Design the resource card using culturally appropriate images

Still to do:

• Source funding for the production and maintenance of the resource card
• Appoint a person to oversee production and updating of the resource card
• Produce adequate numbers of the resource card
• Update the information on the card as required
• Make the card available through the Wurundjeri Website, the Wurundjeri Wellbeing Centre and other avenues

Evaluation

Monitor uptake of the Community Services Card and periodically assess satisfaction with the information provided.
WELCOME TO COUNTRY PACK

Purpose:

To orient/Welcome A&TSI community off Country to Wurundjeri Country

Project aims:

- To provide information about the traditional owners
- To increase the visibility of the Wurundjeri Land and Tribal Council
- To increase connection with the Wellbeing team of the Wurundjeri Land and Tribal Council.
- To provide information and resources to support physical and mental health
- To provide nutrition information
- To provide information about services
- To provide information about community events

Target group:

Melbourne-based Aboriginal people with chronic disease who are experiencing depression via Aboriginal service providers.

Key needs addressed:

<table>
<thead>
<tr>
<th>Need for pride</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to welcome off Country</td>
</tr>
<tr>
<td>Need for connection with community/culture</td>
</tr>
<tr>
<td>Need for Information</td>
</tr>
<tr>
<td>Need for information about services</td>
</tr>
</tbody>
</table>
Key strategies

Already undertaken:

- Create list of information resources to be included in dilly bag/ backpack
- Create specific Wurundjeri Welcome resource(s) to introduce traditional owners
- Items and funding sourced from Colgate, RMH, Austin and City of Melbourne

Still to do:

- Seek sponsors to design and print bag / backpack
- Collate resources
- Dispense Welcome Packs via AHLO, AHPACC, Social workers
- Trial dissemination of 30 bags at three major metropolitan hospitals
- Seek sponsorship to ensure sustainability of the initiative

Evaluation

- Feedback from service providers regarding dissemination and contents
References


12. National Health and Medical Research Council Aboriginal and Torres Strait Island Research Agenda Working Group. The NHMRC road map: a strategic framework for improving Aboriginal and Torres Strait Islander health through research. National Health and Medical Research Council, Canberra. 2002

Appendix I: Service Provider Project Information Sheet Study 1

Project Information Sheet

A Wurundjeri Council Initiative: Improving the wellbeing of members and Melbourne-based Aboriginal people with chronic disease

Researchers
Dr Barbara Murphy, Heart Research Centre
Dr Rosemary Higgins, Heart Research Centre
Ms Karmen Jobling, Heart Research Centre
Aunty Diane Kerr, Wurundjeri Tribe Land and Compensation Cultural Heritage Council
Dr Phyllis Lau, Department of General Practice
Dr Marian Worcester, Heart Research Centre

This project is funded by beyondblue Victorian Centre of Excellence and has been approved by the Human Research Ethics Committee at The University of Melbourne.

Why are we conducting the project?

Mental health has a big part in being well. People with one or more long term conditions like diabetes, heart disease, lung disease or kidney disease can also feel unhappy, worried or depressed. The Wurundjeri Tribe Land and Compensation Cultural Heritage Council are opening an education, culture and wellbeing centre, called the Ngarnga Wulenpuri Centre. At the centre, we want to run programs to help members look after their mental health and wellbeing. We want to talk with staff who work with urban Aboriginal community about their experiences working with this group and staff's associated training needs. This information will greatly help us to make sure the programs at the Ngarnga Wulenpuri Centre are linked with other services and help the Wurundjeri community and Aboriginal people living in Melbourne look after their mental health.

What will I be asked to do?

As a service provider to the Melbourne Aboriginal community, we are asking you to be interviewed by one of our research officers. You may request an Aboriginal research officer, if that will be more comfortable for you. The interview will take about 30 to 45 minutes and will be at a time and place handy to you.
Do I have to take part?

Your involvement is completely voluntary. You do not have to take part if you do not want to. Even if you agree to take part now, you can withdraw at any time without having to give a reason. If you withdraw, any information from you that has not been processed will be removed.

You have been invited to participate because you work with Aboriginal people with chronic conditions in Melbourne. Whatever information you provide will not affect your current work or position. There is a very small chance you may become upset during the interview. If this happens, please let us know, and we may stop the interview immediately.

How will I receive feedback?

We will be inviting you to a feedback session once the project is finished to let you know what we found. A short summary of the project results will also be available to you if you would like a copy. We hope to put the information together and get it written up in a journal or present at a conference.

How will my privacy and confidentiality be protected?

No names or personal information will be given to people outside the project or in any project report. Unless you give your permission, all the information you give will be given codes to make sure it cannot be named to you or any other persons. However, there is a possibility that someone in the community may still be able to identify you from project reports because of the small number of people involved in the project.

To make sure we get all the valuable information you are giving, we will need to audiotape the interview. If you wish, you may read the notes taken from the tape or listen to the tape and give your comments after the interview. Please let me know if you do not want the interview to be tape-recorded.

All information transcribed from the tape recording of the interviews will be destroyed after 5 years.

How do I agree to take part?

If you would like to take part, please read and sign the accompanying consent form and return it in the envelope provided or contact Karmen Jobling on 9326 8544 (ph), 9326 5066 (fax) or at karmen.jobling@heartresearchcentre.org. The research team will then contact you to arrange a time and place convenient for you to be interviewed.

Where can I get further information?

If you want to find out more about the project, please contact Karmen Jobling. If you have any questions or concerns about the conduct of the project, you are welcome to contact The Executive Officer, Human Research Ethics, The University of Melbourne on 8344 2073 (ph) or 9347 6739 (fax).
Appendix II: Service Provider Consent Sheet Study 1

Project Consent Sheet

A Wurundjeri Council Initiative: Improving the wellbeing of members and Melbourne-based Aboriginal people with chronic disease

Participant’s Name:
Address:
Phone/Mobile:
Email:

Please tick √ if you agree with the following statements:

☐ I agree to take part in this project.

☐ The project has been explained to me, I understand what the project is about and I have been provided with a written Project Information Sheet to keep.

☐ I understand that this project is for research purpose only and it has been cleared by The University of Melbourne Human Research Ethics Committee.

☐ I understand that this consent form once signed will be kept by the researchers.

☐ I am voluntarily taking part in the interview/focus group and may opt out at any time and withdraw any unprocessed information I have given without giving a reason.

☐ Whatever information I provide will not affect my work or my position with my employer.

☐ I agree that the researchers may use the results as described in the project information sheet.

☐ I understand that my name and personal details will not be revealed to people outside the interview or in any project report or publications. All the information I give will be confidential and coded in any publication to make sure I cannot be identified, unless I give my permission.

☐ I understand that even though everything will be done to protect my privacy, there is a small chance that someone in the community may still be able to identify me from project reports and publications because of the small number of people involved in the project.
I give my permission for the interview/focus group to be audio-taped and the records of it to be used only for this project.

I would like to have a summary of the project report when it is available. Posted or Emailed.

I would like to be invited for the feedback session at the end of the project.

Participant’s Signature: ____________________________ Date: __________

Please sign and return in envelope provided to Karmen Jobling, Heart Research Centre, Box 2137 Post Office, The Royal Melbourne Hospital, Vic 3050.
Appendix III: Service Provider Interview Schedule Study 1

A Wurundjeri Council Initiative: Improving the wellbeing of members and Melbourne-based Aboriginal people with chronic disease who are experiencing depression, anxiety or related mental health disorder

Interview Questions for Aboriginal Service Providers

Introduction

I’m {name} from {organisation name} and I am working with Aunty Di to help set up a program for the Wurundjeri community and Melbourne-based Aboriginal people with chronic disease who are experiencing depression, anxiety or related disorder. We are consulting with you as an Aboriginal {job title} to learn more about the experiences and needs of Aboriginal community members with chronic disease who are experiencing depression, anxiety or related disorder. We also want to find out about how confident you feel with working with this client group and what things might help to support you to work with this client group.

Participation in this interview is completely voluntary and you can stop the interview at any stage, without giving a reason.

The interview will take about 30-40 minutes. Are you OK if I record the interview? Thanks. We are recording from now.

Questions

- How are people referred to your service?

- How would you describe depression to someone who has never heard of it before?

- In what ways do you see depression affecting clients?
  Qualifier: What effects does depression have on people in everyday life?

- How would you describe anxiety to someone who has never heard of it before?

- In what ways do you see anxiety affecting clients?
  Qualifier: What effects does anxiety have on people in everyday life?

- What kind of things do you do with or for, a patient with chronic disease who is experiencing depression, anxiety or a related disorder? Do you do anything differently to what you would do with your other clients? What would you do differently? How does this benefit the client?
• What is your understanding of the client’s journey to manage their mental health? Do you have a story that you would like to share?

• What gaps do you see in health care for patients with chronic disease who is experiencing depression, anxiety or related disorder? How might you address the gap(s)?

• What do you see as the barriers for clients to see you or access services to help with managing their mental health? How would you overcome these barriers?

• What things make it easier for patients to see you and access services to help with managing their mental health?

• What kinds of professional support and/or training might help to (further) increase your confidence to work with clients with chronic disease who are experiencing depression, anxiety or related disorder?

• Do you have any final comments about the client group, services and programs, training and education or mental health and chronic disease?

Thank you for your time.
Appendix IV: Invitation distributed electronically to Service Providers for Study 2

To whom it may concern,

Wurundjeri Tribe Land Compensation Cultural Heritage Council Incorporated (TLCCHC) is currently working on a chronic disease and wellbeing project in partnership with the Heart Research Centre and The University of Melbourne’s General Practice and Primary Care Health Care Academic Centre. The funding body for this project is beyondblue Victorian Centre of Excellence. The project is titled:

“Improving the wellbeing of Melbourne-based Aboriginal people with chronic disease and experiencing depression, anxiety or a related mental health disorder: A Wurundjeri community-driven initiative”.

The project, which is known as Bundap Marram Durn-Durn (BMDD), or ‘Good’ ‘Mind’ ‘Body’ in Woiwurrung language, was launched in 2010 and commenced in early 2011. It has two separate phases. The first phase of the project is now complete. It involved talking with workers who support and provide services to the urban-Aboriginal community who have chronic health issues and who are also experiencing depression, anxiety and other related wellbeing concerns. Workers from seventeen different organisations participated. Both Aboriginal specific and non-Aboriginal services and their workers contributed their time and stories to make phase one of the project successful. If you would like information about the preliminary findings from the first part of the project, please request a copy of the Project Reference Group power point presentation from the BMDD Project Manager, Ms Karmen Jobling, via karmen.jobling@heartresearchcentre.org or via phone 9326 8544.
The second phase of the project has commenced and we need your support to make it a success.

The second phase of the project will explore how to better support urban-Aboriginal people with one or more long term medical conditions like kidney disease (such as diabetes), heart disease, liver disease, cancer, lung disease (emphysema, asthma) and arthritis. Often people with chronic diseases can feel unhappy, worried or depressed. The project team would like to speak with members of the urban-Aboriginal community who have BOTH a chronic physical illness as well as depression, anxiety and related wellbeing concerns.

Wurundjeri Elder, Aunty Di Kerr and Karmen Jobling, the BMDD Project Manager, are the primary interviewers for this project. Both Aunty Di and Karmen has spoken with many Aboriginal workers and community members as part of the project over the last 12 months about the experiences of community managing chronic disease in the context of wellbeing challenges such as depression and anxiety. These conversations would be held at a time and location determined by community. So please tell us what might work. The information would be audio-recorded and all information provided would be kept confidential. Participating community members would receive a $50 Coles gift voucher in appreciation for their time and contribution to the project.

What are the benefits of being involved?

By talking with community members who have both a chronic disease and other wellbeing concerns, the project hopes to identify strengths and also any gaps that might exist in the services currently available to all Melbourne based Aborigines experiencing similar wellbeing challenges. In addition to this, the information gathered will be used to advise the Wurundjeri (TLCCHC) about what programs or resources might be most beneficial to community. The Wurundjeri (TLCCHC) will then determine whether such programs or resources could be provided by their Wellbeing Centre.

Would you like to take part?

If you would like to take part, or have any questions, please contact Karmen Jobling, the BMDD Project Manager via karmen.jobling@heartresearchcentre.org or via phone 9326 8544.

Kind regards,
Karmen Jobling on behalf of the Bundap Marram Durn-Durn team
Appendix V: Flyer distributed electronically to Service Providers for Study 2

Are You Willing To Share Your Health Story To Help Others?
Do you have one or more of the following health challenges?

- Lung Disease
  Breathing problems such as Asthma, emphysema
- Liver Disease
  Hepatitis, cirrhosis
- Cancer
- Diabetes
- Kidney Disease
  Kidney failure
- Circulatory Diseases
  Heart disease, high blood pressure, high blood sugar, stroke & aneurism
- Auto-immune Disease
  Rheumatoid Arthritis, Psoriasis, Inflammatory Bowel Disease, Thyroid problems (Graves’ Disease) and Type 1 Diabetes

Do these health challenges make you worried, sad, frustrated or angry?

Wurundjeri Elder Aunty Di Kerr and Karmen Jobling, workers from the Bundap Marram Durn-Durn Project will be available to speak with community members who’d like to share their health & wellbeing stories.

Where: Location is flexible (community centres, libraries, parks, you tell us!)
When: A time that suits you!

Small groups from the community can speak with Karmen, either alone, or with another Bundap Marram Durn-Durn project worker (Aunty Di Kerr). Wellbeing stories will be audio-recorded and your information will be kept private. The information you share will be used to assist the urban Aboriginal Community with similar health & wellbeing challenges. If you would prefer to speak with Karmen and/or Aunty Di alone, this can be also be arranged.

Questions?
If you have any questions, please contact Karmen Jobling, the Heart Research Centre’s Project Manager for Aboriginal Programs via karmen.jobling@heartresearchcentre.org (ph: 9326 8544) or Aunty Di Kerr via dianekerr_13@yahoo.com.au or (ph: 0421 624 470).
Project Information Sheet

A Wurundjeri Council Initiative: Improving the wellbeing of members and Melbourne-based Aboriginal people with chronic disease

Research
Dr Barbara Murphy, Heart Research Centre
Dr Rosemary Higgins, Heart Research Centre
Ms Karmen Jobling, Heart Research Centre
Aunty Diane Kerr, Wurundjeri Tribe Land and Compensation Cultural Heritage Council
Dr Phyllis Lau, Department of General Practice
Dr Marian Worcester, Heart Research Centre

This project is funded by beyondblue Victorian Centre of Excellence and has been approved by the Human Research Ethics Committee at The University of Melbourne.

Why are we conducting the project?

Mental health has a big part in being well. People with one or more long term conditions like diabetes, heart disease, lung disease or kidney disease can also feel unhappy, worried or depressed. The Wurundjeri Tribe Land and Compensation Cultural Heritage Council are opening an education, culture and wellbeing centre, called the Ngarnga Wulenpuri Centre. At the centre, we want to run programs to help members look after their mental health and wellbeing. We want to talk with you and other local Aboriginal people with chronic conditions who are feeling unhappy, worried or depressed to find out about your story and what might help you to look after your mental health. This information will greatly help us to make sure the programs at the Ngarnga Wulenpuri Centre are linked with other services and help the Wurundjeri community and Aboriginal people living in Melbourne look after their mental health.

What will I be asked to do?

As a Melbourne-based Aboriginal person, we are asking you to be part of a focus group of about 4-12 Aboriginal people with chronic conditions who are feeling unhappy, worried or depressed. The focus group will be run by an Aboriginal facilitator and participants will be encouraged to be respectful of each other's privacy and their stories. The focus group will take about 60 to 90 minutes, and you will be offered a $50 voucher to assist you with traveling to and from the venue. If you want to share your story and what could help you but feel very uncomfortable in a group, where possible, we may be able to organise an interview instead.
Do I have to take part?

Your involvement is completely voluntary. You do not have to take part if you do not want to. Even if you agree to take part now, you can withdraw at any time without having to give a reason. If you withdraw, any information from you that has not been processed will be removed.

You have been invited to participate because you have one or more chronic condition(s) and have been feeling depressed, anxious or out of control. Whatever information you provide will not affect any service you currently receive. There is a very small chance you may become upset during the interview. If this happens, please let us know, and we may stop the interview immediately.

How will I receive feedback?

We will be inviting you to a feedback session once the project is finished to let you know what we found. A short summary of the project results will also be available to you if you would like a copy. We hope to put the information together and get it written up in a journal or present at a conference.

How will my privacy and confidentiality be protected?

No names or personal information will be given to people outside the project or in any project report. Unless you give your permission, all the information you give will be given codes to make sure it cannot be named to you or any other persons. However, there is a possibility that someone in the community may still be able to identify you from project reports because of the small number of people involved in the project.

To make sure we get all the valuable information you are giving, we will need to audiotape the interview / focus group. If you wish, you may read the notes taken from the tape or listen to the tape and give your comments after the interview / focus group. Please let me know if you do not want the interview / focus group to be tape-recorded.

All information transcribed from the tape recording of the interviews or focus groups will be destroyed after 5 years.

How do I agree to take part?

If you would like to take part, please read and sign the accompanying consent form and return it in the envelope provided or contact Karmen Jobling on 9326 8544(ph), 9326 5066(fax) or at karmen.jobling@heartresearchcentre.org. The research team will then contact you to arrange a time and place convenient for you to be interviewed / attend a focus group.

Where can I get further information?

If you want to find out more about the project, please contact Karmen Jobling. If you have any questions or concerns about the conduct of the project, you are welcome to contact The Executive Officer, Human Research Ethics, The University of Melbourne on 8344 2073 (ph) or 9347 6739 (fax).
Appendix VII : Community Project Consent Sheet: Study 2

Project Consent Sheet

Improving the wellbeing of Melbourne-based Aboriginal people with chronic disease and experiencing depression, anxiety or a related disorder: A Wurundjeri community-driven initiative.

Participant’s Name:

Address:

Phone/Mobile:

Email:

Please tick √ if you agree with the following statements:

☐ I agree to take part in this project.

☐ The project has been explained to me, I understand what the project is about and I have been provided with a written Project Information Sheet to keep.

☐ I understand that this project is for research purpose only and it has been cleared by The University of Melbourne Human Research Ethics Committee.

☐ I understand that this consent form once signed will be kept by the researchers.

☐ I am voluntarily taking part in the interview/focus group and may opt out at any time and withdraw any unprocessed information I have given without giving a reason.

☐ I understand that there may be a very small chance I may feel uncomfortable in the middle of the interview. If this happens, I may ask for the discussion to be stopped immediately.
Whatever information I provide will not affect the level of care I am receiving now from the Council or service participating in the project.

I agree that the researchers may use the results as described in the project information sheet.

I understand that my name and personal details will not be revealed to people outside the interview or in any project report or publications. All the information I give will be confidential and coded in any publication to make sure I cannot be identified, unless I give my permission.

I understand that even though everything will be done to protect my privacy, there is a small chance that someone in the community may still be able to identify me from project reports and publications because of the small number of people involved in the project.

☐ I give my permission for the interview/focus group to be audio-taped and the records of it to be used only for this project.

☐ I would like to have a summary of the project report when it is available. Posted or Emailed.

☐ I would like to be invited for the feedback session at the end of the project.

Participant’s Signature: Date:

Parent’s or Guardian’s signature (if participant <18 years old) Date:

Name, address and phone no. of parent/guardian:

Please sign and return in envelope provided to Karmen Jobling, Heart Research Centre, Box 2137 Post Office, The Royal Melbourne Hospital, Vic 3050.
Introduction

Acknowledgement of and/or Welcome to Country

My name is xx xx, I'm a researcher from the xxxx, name of town/city.

Thank you for agreeing to take part in this focus group. The project that you are participating in involves setting up a program to look after the well-being of the Wurundjeri community and Melbourne-based Aboriginal people with chronic disease. The purpose of today’s session is for us to gather your views and experiences to assist us with developing the program. First though, I’d like to start by saying that its important for me to cover everything I need to cover and also to gather views from as many people as possible, so I’m going to try to keep everyone on track, and also make sure everyone gets a turn to have their say – so if I interrupt or appear to change the topic suddenly, that’s just me keeping to my schedule

Also, may I confirm that you have read and understood the project information given to you at the start of the program, and you have given your consent to be part of this focus group, and for the focus group to be audio-recorded?

[If necessary, go through project information and consent form again. Otherwise proceed to the questions.]

Questions

- How did you first find out about your chronic disease? Would anyone like to share their story?
  Qualifier: You can give as little or as much detail about what happened, as you are comfortable
- When was the last time you went to a health service or doctor or program or group to help you manage your health?
  Qualifier: Which one did you go to? Would anyone like to share their story? You don’t need to go into detail about results; you can give as little or as much detail about what happened at the visit, as you are comfortable.
• Can anyone share a bit about their experiences of mood difficulties – things like feeling sad, down or hopeless? What areas of your life has feeling down, hopeless or sad had an effect
  Qualifier: Have feelings of depression affected relationships, work, family, money, housing, education, connection to Country and/or Elders, moods, sports, health, etc

• Can anyone share a bit about their experiences of things like feeling worried or anxious?. What areas of your life has feeling worried had an effect?
  Qualifier: Has anxiety affected relationships, work, family, money, housing, education, connection to Country and/or Elders, moods, sports, etc

• What do you think are the gaps in Melbourne services for Aboriginal people with chronic disease who are (use appropriate words from the group’s definitions of depression and anxiety)?
  Qualifier: Why is it a gap? Who do you think would use the service or program?

• What stops you using services to help you manage your mental health? How do you think these barriers could be broken down?

• What things make it easier for you to use services to help you with managing your mental health?
  Qualifier: What are the key aspects of a program or service that would help you to feel healthy and happy with life?

• Do you have any final comments about the services and programs, mental health or chronic disease?

Thank you for your time
### Appendix VIII Bundap Marram Durm Durm Resource card

<table>
<thead>
<tr>
<th>Resource</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASK</td>
<td>1800 175 175</td>
</tr>
<tr>
<td>VAHS</td>
<td>9419 3000</td>
</tr>
<tr>
<td>VAHS Family Counselling</td>
<td>9403 3300</td>
</tr>
<tr>
<td>Bunurong Health Service</td>
<td>9794 5933</td>
</tr>
<tr>
<td>beyondblue info line</td>
<td>1300 22 4636</td>
</tr>
<tr>
<td>Directline - Drug &amp; Alcohol Counselling &amp; Info</td>
<td>1800 888 236</td>
</tr>
<tr>
<td>Gambling Helpline</td>
<td>1800 858 858</td>
</tr>
<tr>
<td>Lifeline</td>
<td>13 11 14</td>
</tr>
<tr>
<td>Mensline Australia</td>
<td>1300 789 978</td>
</tr>
<tr>
<td>Relationships Australia</td>
<td>1300 364 277</td>
</tr>
<tr>
<td>SANE Helpline</td>
<td>1800 187 263</td>
</tr>
<tr>
<td>Sexual Assault Crisis Line</td>
<td>1800 806 292</td>
</tr>
<tr>
<td>Southern Health AHLO</td>
<td>9554 1000</td>
</tr>
<tr>
<td>Suicide Line(VIC)</td>
<td>1300 651 251</td>
</tr>
<tr>
<td>Women's Domestic Violence Crisis Service of Victoria (24 hr line)</td>
<td>1800 015 188</td>
</tr>
</tbody>
</table>