



Interaction Matters!

The Experiences of Diverse Residents of Shepparton using Health Services



Zubaidah Mohamed Shaburidin, Mujibul Anam, Olivia Mitchell & Lisa Bourke
Department of Rural Health, The University of Melbourne

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The researchers acknowledge and pay respect to the Traditional Owners of the lands upon which our campuses are situated and across the Goulburn Valley Region where this research took place. We would like to pay our respects to the Elders past, present and emerging.

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For more information, please contact Dr Olivia Mitchell at the Department of Rural Health, The University of Melbourne at Olivia.mitchell@unimelb.edu.au.

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The Experiences of Diverse Residents of Shepparton using Health Services

Executive Summary

Greater Shepparton region represents one of the most culturally and socially diverse areas of regional Victoria with a large population of First Nations people and over 50 nationalities speaking more than 40 languages. Therefore, providing health care that is inclusive is particularly important. Other studies have found that people from diverse groups may not feel safe, confident and included when seeking health care.¹⁻⁶ Evidence is clear that when health services are not culturally appropriate, inclusive and welcoming, people needing health care are less likely to use them.^{1,4,7-10} This report presents research that explored Shepparton residents' perspectives of access to and use of health services, with particular attention to the perspectives of residents from socially and culturally diverse backgrounds. It is the intention of this report to prioritise the voices of Shepparton residents from socially and culturally diverse backgrounds to inform how healthcare can be delivered inclusively and tailored to local needs.

The research team recruited participants by attending community events, community group meetings and meetings with key individuals from culturally and socially diverse sections of the community. Community spaces and organisations that researchers visited include places of worship, community hubs, Men's Sheds, tertiary education providers and community organisations. In addition, to seek out residents who may not be involved with particular community organisations, researchers also visited public places around Shepparton (such as the skate-park and neighbourhood parks) and asked people in these locations if they would like to participate in the research. Further, four community co-researchers were employed to assist in recruitment of participants who are young, First Nation, new arrival and culturally diverse in other ways. Using this method, 119 community members participated in this study, including 76 individual interviews, 15 small group interviews, and five focus groups. Participants had diverse social and cultural identities, including 12 First Nation participants, 63 people from non-English speaking backgrounds (including 12 refugee or asylum seeker participants), 24 young people, 15 residents identifying as LGBTIQ+ and 43 parents. Many could be grouped into more than one of the above groups.

This report describes the complexity of experiences of accessing and using health services for residents of Shepparton and surrounding towns. These residents' experiences are a combination of simultaneously positive and negative stories, with the majority of participants describing health services as generally "good." Many are appreciative of the availability of services and caring, respectful and genuine health professionals.

Participants also suggested ways that health services could improve so that they are more accessible for everyone. Exclusionary practices occur in various ways and this report has demonstrated that people of all backgrounds can, and have, experienced these in health services as well as in other arenas. Communication was the key area for exclusive practices, and situations were described where health service users felt judged, disrespected, intimidated or assumptions were made about their social and/or cultural identity.

Participants were asked for suggestions on ways that health services can improve and provide quality care. Almost half of all participants articulated ways that interactions and communication between health professionals and patients/clients can be improved. These include:

- Being welcoming in body language (e.g., smiling, engaging in small talk, body language, facing the patient/client rather than the computer/interpreter/parent)
- To not make assumptions about a patient/client's identity, culture, preference or health issue
- To communicate in ways that reflect the practitioner seeing the patient/client in human ways with varying capacities and needs
- Showing care, transparency of the health processes and thoroughness
- Taking the time to listen to patient/client's concerns
- Being respectful and free of judgement, regardless of patient/client views
- Communicating waiting times, cost and other service protocols for patients/clients in order to manage expectations

The study highlights that participants have different experiences and expectations from health services. Negative experiences of accessing health services in the past leads to disengagement with health services, both currently and in the future. Therefore, this study presents six key messages:

- (i) Avoid making assumptions about patients/clients and their needs or preferences based on obvious identities and/or social and physical factors
- (ii) Practice in ways that are genuine, caring and compassionate
- (iii) Provide information about the service, its availability, cost and how to access the service
- (iv) Listen to, respect and act on patient/client requests where possible, even if they are not considered the priority for the health professional
- (v) Tailor care for individual patients/clients and their families
- (vi) Acknowledge that patients/clients are unwell, may be stressed, may be intimidated and may have had past negative experiences with other services

It is hoped these findings can contribute to how Shepparton services can continue to be responsive, accessible and respectful to the many culturally and socially diverse members of our community. Overall, this study found that health services and professionals are usually welcoming, respectful and responsive, without judgement or assumption.

Interaction Matters!

The Experiences of Diverse Residents of Shepparton when using Health Services

What is the study about?

Greater Shepparton region represents one of the most culturally and socially diverse areas of regional Victoria that started with a resilient, vibrant and significant presence of First Nations peoples' and is now home to over 50 nationalities speaking more than 40 languages. Therefore, providing health care that is inclusive is particularly important in Shepparton. Further, the rural issues of less choice of services, fewer Specialist services and greater health need than in metropolitan areas identified in earlier research^{5,11,12} further highlight the need for inclusive health care. Other studies have found that people from diverse groups may not feel safe, confident and included when seeking health care.¹⁻⁶ Evidence is clear that when health services are not culturally appropriate, inclusive and welcoming, people needing health care are less likely to use them.^{1,4,7-10} This research explored Shepparton residents' perspectives of access to and use of health services, with particular attention to the perspectives of residents from socially and culturally diverse backgrounds.

Realising the importance of inclusion and access to care for socially and culturally diverse groups, the Victorian government has designed and implemented a variety of policies with the aim of improving access to and use of mainstream health services for diverse peoples such as Australian First Nations peoples,^{13,14} people with disability,¹⁵ people who are older,¹⁶ young people,¹⁷ people from immigrant and refugee backgrounds,¹⁸ people who identify as lesbian, gay, bisexual, transsexual, intersex, queer, asexual and questioning (LGBTIQA+),¹⁹ and people from many other diverse and intersecting groups. A key element of these initiatives is seeking out, responding to and engaging with groups within the local population who are not regular service users or frequently report negative experiences in using generalist health services. Within this policy context and recognising the important role 'mainstream' services play in providing health care to everyone in the community, many of these services have undertaken a range of initiatives to increase the inclusivity of their service for diverse groups of people.^{5,20}

It is the intention of this report to present and prioritise the voices of Shepparton residents from socially and culturally diverse backgrounds to inform how healthcare can be delivered inclusively and tailored to local needs. Many participants of the study spoke about their experiences using local health services but some also spoke about using health services in other rural towns and in metropolitan cities. While some participants expressed specific issues and stories, there were many that shared experiences of inclusion and exclusion. This report identifies some of the common ways that in/exclusion can be experienced and provides examples of how their experiences of using health services were enhanced or impeded. It is hoped these findings can contribute to how Shepparton services can continue to be responsive, accessible and respectful to the many culturally and socially diverse members of our community.

How was the study conducted?

The data drawn on for this report is part of a larger project conducted with four mainstream health services across the Goulburn Valley. This research seeks to provide evidence about how mainstream rural health services can become more inclusive and welcoming for everyone in the community. This research project received ethics approval from The University of Melbourne Human Ethics Committee.

Before data collection, researchers built relationships with key individuals, organisations and community groups within Shepparton over a period of 18 months. The research team consulted with and recruited participants for this project by attending community events, community group meetings and meetings with key individuals from culturally and socially diverse sections of the community. Community spaces and organisations that researchers visited include places of worship, community hubs, Men's Sheds, tertiary education providers and community organisations. Building relationships and trust took time and provided researchers with understanding of the context of these groups and individuals. Some places were visited once or twice and others were visited multiple times. In addition, to seek out residents who may not be involved with particular community organisations, researchers also visited public places around Shepparton (such as the skate park and neighbourhood parks) and asked people in these locations if they would like to participate in the research.

During this process, researchers recruited and employed four community co-researchers to promote the research, support relationship building, aid in recruitment and/or conduct interviews within their respective networks. Sometimes the co-researchers conducted interviews and small group interviews and at other times it was more appropriate for the co-researchers to recruit participants for others in the project team to interview; this was negotiated between the participant and the co-researcher. Regardless of interviewer, all participants were given a Plain Language Statement describing the study and asked to sign a consent form prior to their participation. In addition, participants were all provided with a \$30 gift card as an appreciation of their time and contribution.

Using this method, 119 community members participated in this study. Diverse approaches were used to gather participant perspectives where 76 people participated in individual interviews, 15 were interviewed as part of a small group of 2-3 people, and 28 were included in five focus groups. Focus groups consisted of existing groups or groups that were promoted by local organisations. Two participants from the focus groups, at their request, were later interviewed as they wanted to tell their story in detail. Regardless of interview type, all participants were asked about their experiences using local health services, expectations of health services, and specific experiences with the four health services. All interviews (except for one where notes were taken instead of being audio recorded at the request of participant), small group interviews and focus groups were audio recorded and transcribed at the consent of participants.

Participants had diverse social and cultural identities, including 12 First Nation participants, 63 people from non-English speaking backgrounds (including 12 refugee or asylum seeker participants), 24 young people, 15 members of the LGBTIQ+ community, and 43 parents. Many could be grouped into more than one of the above groups and other identities and social groupings were also proposed; for example, 79 identified as women and 40 identified as men.

Each transcript was read and coded to identify positive experiences with health services, negative experiences and specific experiences relating to the four specific health services involved in the larger study. Common experiences are presented here along with case studies to highlight particular

issues of in/exclusion and the complexities of accessing health services for people from diverse backgrounds. To protect the anonymity of participants, these case studies are presented as a combination of 2-3 participants that shared common stories gathered in this study.

What did the study find?

This report details exclusionary and inclusionary practices that consumers identified when accessing and using health services. Importantly, researchers found that when asking about health care, participants generally referred to care from General Practitioners and/or the local Emergency Department. As such, in order to gain consumer perspectives regarding use of local allied health services, community health services, mental health services, dental services, imaging services, human services and other types of primary care, researchers prompted participants with additional questions.

The specific issues underpinning in/exclusion are explored and case studies are included to provide more detailed consumer experiences and explain how they weave with previous experiences and other situations in participants' lives. In short, many participants had complex lives and juggled multiple family needs and priorities, of which using health care was only one part.

Despite these complexities, it is important to note at the outset that this study found that the majority of participants were generally satisfied with the health care they received in Shepparton. Furthermore, the majority of participants talked about the high level of care and quality interactions with many different health professionals. They also indicated they were able to identify when health professionals genuinely cared and when they were being rushed through consultations and *"treated like a number."* A sense that a health professional genuinely cared was important for the majority of participants and most also wanted health professionals to assess their health and wellbeing overall. A holistic approach to health care was usually preferred rather than a focus on only one issue at a time.

Supporting access to health care

While there were stories of issues, problems and challenges, there were also stories where local residents spoke about quality care, being treated with respect, and highlighted professionals who were caring, responsive and sensitive. Among focus group participants, some health professionals were reported as communicative, some services met expectations and were described as available when needed, and some of the services were talked about as being culturally safe and respectful. This section highlights what underpins these experiences of inclusion and what can be learnt from these experiences. Some of these experiences highlight practice that leads to service users feeling included, welcomed and safe.

What has worked for health service users?

Doctors

Participants shared experiences of health care that were positive. Almost half of the interviewees spoke favourably about accessing health care from doctors/GPs. Specifically, 10 participants described positive experiences with their GP due to clear explanations and 11 participants reported

that their GP listened to them during consultations. A few interviewees spoke about the usefulness of having a family GP. Some also spoke about having increased confidence in their care when a GP is thorough and a couple spoke about the non-judgemental attitude of their GPs. For example, a focus group participant stated: *“I just find that anything that I go to him about, if he doesn’t know fully in his own mind what the problem is, he’ll research it and then the next appointment, yeah. It’s all sorted and yeah.”*

Further, 14 participants, including a First Nations participant, had positive experiences with accessing a GP from a similar background to them where they highlighted communication as key to their experience. A few found it helpful when a GP spoke the same language but many found it easier to communicate with a GP with similar life experience, including seeing a GP of the same sexuality or a GP from an immigrant background. One interviewee described this preference as: *“the fact I’m a lesbian. I don’t know... I’m not sure. It makes me... I prefer to see a female [doctor]. I just think that a female kind of understands me better.”* A few specifically discussed the local Emergency Department and described it as *“helpful”*; five participants specifically named their local regional hospital’s nurses as *“being kind.”*

Holistic care

Others spoke favourably about non-medical care. In one focus group, one of the participants shared their experience with a nurse; the nurse was very supportive and the client developed a strong interpersonal relationship with them. In the same group discussion, another participant talked about a supportive social worker. Overall, health consumers indicated feeling included when they receive care that meets their needs. Some suggested that non-medical services are *“more holistic.”* Others described instances whereby a friend or a case worker had assisted them in navigating the health system that led to accessing appropriate care. Three interviewees specifically mentioned that they would only access care if a worker was able to accompany them to appointments. Some have mentioned other ways that have helped them access care, such as when health services book interpreters (either for language and/or ability), the availability of bulk-billing, a carer taking them to appointments, and choosing to seek health care treatment overseas due to cost and affordability. One teenage mother shared a story on how she felt cared for by a Maternal and Child Health Nurse who took her to an appointment that she was not confident attending by herself.

Case Study 1: Holistic Care as Client-Centred Care

Ari was born with a disability and has had to access specific disability services her whole life. In addition, she has various other health issues that require management. She has a case worker to support her to manage her condition as well as other health issues that arise. Some of the support Ari receives includes assistance when attending appointments to see allied health professionals, a GP and Specialists, and this is often by the case worker. The support and company are especially useful when Ari has to go to Melbourne to attend Specialist appointments. Ari is sometimes anxious that she might not be able to understand or remember what health professionals have said, so she finds the support provided by the case worker helpful and comforting. Although Ari has seen various health professionals her whole life, she still doesn’t feel confident going into a health service on her own; it puts her at ease when her case worker and some allied health professionals visit and deliver services in her home.

Positive interactions

Many participants spoke about their expectations from health services and shared what they think good practices could look like. An LGBTIQ+ focus group participant commented: *“I felt respected. I felt accepted. I felt, you know, my gender was no kind of... it wasn’t taken into account, my mental health was first and foremost. My gender wasn’t the primary thing that they were looking at so that’s really cool.”* Within these discussions, most talked about the importance of the interactions they have with health professionals, including friendliness, feeling welcomed, being listened to, being treated with respect, health professionals taking time, health professionals demonstrating that they cared for their patients/clients, being provided with extensive information, attending to their needs and behaving in a professional manner. One Arabic-speaking young father summed it up as:

It’s all to me respect and communication is the key to delivering service, to engaging with people, to unpacking conversations and actually understanding what people need, truly need...Those are the common sense things that people that have been in their jobs for 30 years will never be able to understand because they’ve been so pushed down by the system and the way that the computer tells you to do things you miss it, you lose it.

Some interviewees shared instances where this has occurred and a few provided examples where health professionals took a holistic approach to their treatment. One participant recalled how a health professional used visual aids to help them understand health issues while two other participants spoke about the genuine care they felt when health professionals telephoned them to follow-up and check on their health. A few interviewees also spoke about the support they received from health professionals throughout a referral process. Other aspects of good practice identified by participants included being seen quickly, being offered a cup of coffee or tea, and health professionals believing patients/clients. As a small group interviewee expressed: *“the more connection you have with the client, the more chance that they’ll keep coming back.”*

Some interviewees spoke about the importance of feeling safe in a health service and for health professionals to be culturally aware of their needs. One First Nation participant spoke about the need for health services to engage with Traditional Owners and local First Nations peoples:

If there is any meetings around health, invite our mob in there and have that discussion. If you are doing a workshop, get an Elder in to talk or somebody in to have a conversation around Aboriginal engagement. It’s very important. Don’t just sit around and think you know us because you don’t.

Other forms of good practice included services that were available, accessible when needed (including after office hours for some), and supportive. Some discussed service providers that were *“welcoming”* and *“understanding,”* including one small group interviewee who commented that: *“Yeah and, you know, like few times I had to cancel my appointment, you know, and, you know, sometimes if you cancel somewhere, they get all, you know, angry. And when I make another one, you know, nothing, change, yeah. They still treat you really lovely.”* Many spoke about the relationships with health care professionals, implying when relationships were positive, communication was more open and honest and better care was believed to be received.

Stories of Exclusion

Barriers to accessing care

There were a range of stories shared by participants about feeling excluded. Some of these stories pertained to particular groups while others were based on experiences of racism, exclusion or hetero-normativity (assumptions that people are White, heterosexual, etc.). These stories included experiences from health care settings but also other sectors and public settings. These experiences were internalised by residents and continued to have an impact when accessing health care services. These experiences led some to feel uncomfortable, anxious or intimidated. Stories of judgement and disrespect occurred in various places, one of which included an interviewee being sworn at on the street due to their physical appearance. Another interviewee described witnessing their parent receiving a verbal scolding from a health professional for their inability to speak English:

A lot of them, I can tell you 90% of the time, the receptionist or be it a nurse, they say you've been here 20 years, how come you don't know English, go and study some English, go and get some English, go and learn some English. And this is horrible to say to someone just trying to be at the health service to get a treatment. It is horrible. Like it happens all the time, even at ultrasounds, x-rays.

Non-Australian born participants often perceived such statements as aggressive and described feelings of inferiority by their lack of ability to respond. Those who had experienced these overt verbal attacks described them as occurring on multiple occasions, in health and other settings.

Some participants talked about cultural exclusion and how services and service providers think in "White" ways. As one participant in a focus group comprising of young people commented: "I don't know if it's to do with, like, the ethnicity, the Australians, but like I'm an ethnic person and they don't get exactly what I'm going through, so they just think yeah..." Another group member followed: "they see as, you're probably going through something a White person would go through and think it's the same" and another member summed up: "Yeah, they're limiting you to other [white] people's expectations." Other participants, especially older participants, wanted to see health professionals from backgrounds similar to their own culture, language, gender and/or sexual identity, citing shared lived experiences. When this was achieved, participants noted this as a positive experience.

Some participants spoke about not wanting to feel different and, in particular, not wanting to be categorised as different or labelled as "high risk" because of their identity. A focus group member commented:

If I tick yes, I am at risk of a higher group, because technically I'm a man who is having sex with other men, then in Australia I'm in a high-risk group for HIV. I have to tick that, I'm in a high-risk group for HIV. And then the new Dentist or the new Receptionist are going to get the form. If their practice isn't inclusive and they look a bit startled when they see it or they go (whisper), beware of this one, there's just that level of discomfort that you have no matter.

Participants who shared these stories of exclusion described feeling hurt, scared and embarrassed. One interviewee found it distressing when recalling these incidents. Another shared how when interpreting for their family members, they sensed mistrust on the part of the health professional; "they think I put things into my own words." Stories were diverse, but judgement and exclusion were felt by many participants and these occurred on multiple occasions in various services and places. For some participants, it was the accumulation of these judgements that preceded feelings

of disrespect, inferiority and not feeling welcome at the particular service. Some noted that the compounding impact of being excluded has led them to avoid and/or not to use services.

Assumptions

Many participants shared instances where they had experienced exclusion in the form of assumptions made by health professionals based on physical appearances, social circumstances or cultural identity. Most participants identified the basis of some of these assumptions. For example, a young mother explained in an interview that while undergoing labour, health professionals treated her in a way that *“assume[d] that the mothers don't know anything because they're 17 and they're just popping out a few kids for things.”* Another spoke about their experience following an accident: *“I think they were under the impression that I just wanted some painkillers, which I didn't. I just wanted to know that I'm not going to die. No broken ribs or anything.”* Two interviewees recalled how health professionals made the assumption that they had gestational diabetes because of their cultural and physical factors:

I kept telling her, oh, sorry, I don't have diabetes. And she kept saying, oh, no, your test results. And I said, oh, and they go, did they not tell you with your previous child? And I said, no, they said I didn't have diabetes. And then she finally went back and she did all the appointments and she goes, oh, no, because it's women like you, meaning my size and my culture, like saying, oh, yeah, because, you know, I noticed XXXX women back home in New Zealand, they, you know, usually overweight and they have diabetes.

Assumptions of hetero-normativity, or assuming clients are white, heterosexual, English-literate, able-bodied and so forth, were also commonly described. One young interviewee recalled how during health consultations their partner was often mistaken for being their housemate or brother. A small group participant described how a health professional had made the assumption that the participant's child was white: *“They actually told me, oh they're not Aboriginal? So, you know how you're meant to say, 'are you Aboriginal, or do you identify as Aboriginal or Indigenous?' It wasn't asked; they told me: you're not Aboriginal... And actually, she is [Aboriginal].”* For some interviewees, health professionals made assumptions of their needs based on their faith. For example, two Muslim women in a small group interview spoke about gender preferences when seeing a health professional, with one stating that she prefers to see a woman whereas the other is comfortable seeing either a male or female health professional.

One participant described their interaction with a health professional where they over-emphasised the need to practise good hygiene following a treatment, assuming that the participant did not understand 'Western' hygiene practices: *“[the discussion on hygiene] dragged for like nearly 35 minutes. Like you come across as helpful but I don't need that extra help...they (health professionals) have this assumption that you are ignorant.”* They reported that the health professional made further assumptions based on the participant's cultural background, suggesting they *“should be appreciative that we're in Australia, we have access to health services and we have to show our appreciation.”*

Another interviewee with a hearing impairment recalled their experience of feeling embarrassed and frustrated after repeatedly asking the health professionals to *“come up and get me from the waiting room when the doctor is ready rather than yell my name.”* Others discussed frustrations

with particular communication requests being ignored and services continuing to assume heteronormativity. In one focus group, a member of the LGBTIQ+ group exclaimed:

Every time I call the GP clinic that myself and my partner go to, the assumption is made by the reception person, admin person, that even though I've been going there for like three years now, that when I say my name and I would like to make an appointment for myself and/or partner, we both see the same GP, it's always "what is his name?" not "what is their name" or "what is your partner's name" and just that one – like it's a constant.

These examples demonstrate the discomfort and lack of safety that participants experienced when using health services. The assumptions made by professionals lead to consumers feeling that their identities are dismissed, disrespected and judged which further impacts how some participants decide to use, or not use, services in future.

Language and communication barriers

Approximately 70% of participants interviewed, including eight First Nations participants as well as additional participants in many of the small groups and focus groups, spoke about various ways that language, communication and feeling unwelcome were barriers they confronted when accessing health care. At times, these exclusionary behaviours pertained to body language, facial expressions and verbal communication. For example, when asked if participants had felt unwelcome in any health services, they frequently replied: *"I never received a racist [comment] or something like that. Never. ...The worst thing is not if someone say it, but if someone's expression, that you understand that someone thinks that you're not good enough to understand their language."* Another participant also shared an incident where a staff member at a human service organisation treated them differently to the person before them:

There was a lady before me. She was Australian. The staff greeted her with a smiling face and said hello and asked how she was. She completed her task. The lady left. It was my turn. When she saw me she got serious. Did not smile at all... The person who was smiling and sweet talking few minutes ago was gone and a solemn faced person was sitting there. I said I brought my report that I got from the doctor. She looked at the report and said that she was sorry but was not able to accept it. She had a grumpy face... I told her that she should have treated me like she treated the lady before me. I said to her you had a smiling face and you were so happy a few minutes ago. Why do you act like this when it is my turn? She said she didn't act differently. I told her that she was different and did not treat me like she did treated the woman in front me, and asked her if she knew how upset I felt. Took my report and just did like this and said 'I don't accept this.' I told her that she might not accept my report. I asked to see the manager. She said that I had to wait a long time to see the manager. I told her to call the manager and added that I could wait until night. I took a seat and she called her manager... I was sure that the headscarf was the reason for her acting like this.

A total of 21 interviewees, including five First Nations participants, described a variety of ways where they were made to feel unwelcome in a health service. One interviewee described this as: *"It just felt like they didn't care. They don't take the time to assist us, and it's like they really don't care,*

they just want you in and out and prescribe you whatever and leave.” Two other interviewees spoke about the impact of feeling unwelcome, with one stating that:

If you're going to make me feel like that I'm not welcome here then I, I won't actually express myself and tell you about everything. I will miss things because I feel like I just need, I already want to go home... I've had enough myself; now that you're pushing me to have enough, I will just go home, you know.

In addition, 14 interviewees spoke about health professionals being rude, of which four specifically described instances where communication felt disrespectful. Another two participants recalled incidents where they had overheard health professionals discussing their cases among each other in a derogatory manner. Some participants also shared instances where miscommunication occurred either between health professionals or during patient-provider interactions.

Most participants suggested that communication and language are the most important factors in ensuring inclusive health care. Communication barriers were described in multiple ways. 13 interviewees, including three First Nations participants, described how medical practitioners did not explain or communicate procedures/diagnoses to them clearly. The use of medical language was problematic for some; one small group participant commented:

...Like, you know how you put some medical terms, and I said to her I don't even understand it and they gave me a form to fill. And honestly, just something, I can't even understand what to, how to answer the questions, so I said to her I need help. I did, I need somebody to help me because I don't even understand. I'm not going to answer the question because I don't even understand those big words.

For others, communication problems centred on service providers “writing too much” and not having enough “eye contact.” A small group member commented “they are too focused on the forms.” Further, 14 interviewees, including four First Nations participants, specifically described instances where they felt health professionals did not listen to their concerns and seven of these participants spoke about health professionals not believing them and/or dismissing their concerns. One young mother described this interaction in the following way.

I did go to a practitioner in (medical centre) and I didn't feel that comfortable in there. She just wanted to know why that I needed a referral to see a psychologist and made me talk about it in there when I wasn't ready to... She was just very blunt and like very, didn't understand how to take domestic violence.

Among interviewees, 16 spoke about the language barrier they and/or a family member experienced when accessing health care. Some talked about the barrier of language as being more problematic for the elderly while others described their struggle to understand ‘medical language.’ One interviewee with a disability described feeling confused/nervous as result of not understanding what was being said. Interviewees who spoke more than one language at home and had lived in Australia for a number of years shared stories of how they were ridiculed and treated with disrespect when they asked for an interpreter. For these participants, they were questioned by health professionals as to the reason why they had not learnt to speak English. One participant described this experience in the following way:

Because I am a person who does not speak English. They say ‘Wait’, I will wait. We called them and ask for a translator. They told us that we have been here [in

Australia] long enough and we should learn it by now... I felt terrible. I wanted to shout, I mean I wanted to scream. Because I couldn't make myself, you know, I was in a foreign place and I was not able to express myself... I would if I knew the language. Okay, I understand some but I have problems in speaking. I couldn't go to school with two kids. My home was not peaceful, my family was not good. I did not have much money. They don't know anything and they keep talking.

Case Study 2: A woman's struggles with language

Sarah has been living in Australia for two years with her husband. Sarah can speak and understand the English language but is not confident in her fluency. Sarah goes to TAFE to improve her fluency but struggles with the teaching style in Australia which is very different to her country of origin. She doesn't feel that her language skills are improving and this impacts on her ability to communicate confidently on a daily basis. She also finds it difficult and confusing to navigate the different ways things are done in Australia, including the differences between Medicare and Health Care cards, the different kinds of dental Specialists, and trying to pass the driving license theory test which is only conducted in English (although Sarah knows how to drive and holds a driving license from her country of origin). Her husband, who has been in Australia longer and through his work is exposed to the way things are done in Australia, takes the time to explain these things to her.

When attending appointments related to her health, Sarah prefers her husband to be there because she is not confident of her ability to understand the health professional nor her ability to make them understand her health issues. She senses this has been frowned upon and there are efforts by health professionals to not include her husband, which she finds disrespectful and scary.

While Sarah is generally positive about health professionals, she says they vary. Some do not provide a lot of information or take the time to be caring and explain what is being done. For example, Sarah and her husband went to the pathology centre for a blood test and was horrified to see that she had started to bleed profusely after the phlebotomist had taken her blood samples. Both Sarah and her husband started to panic, however the phlebotomist was not overly concerned and did not explain why this had happened nor reassured her that she will be fine. Experiences like these make Sarah feel scared of going into health services. Sarah is aware that she has a thick accent and is afraid that health professionals would get frustrated and judge her for not speaking clearly.

Sarah does, however, have a General Practitioner (GP) that she sees for her health issues and does not feel the need to bring her husband with her to those appointments. Her relationship with her GP is one that is friendly and open, with Sarah feeling she is not just another patient and her GP is genuinely concerned with her overall wellbeing. Sarah is comfortable asking questions when she doesn't understand and her GP often helps her make sense of her health issues by using simple language, analogies and visual images. This relationship with her GP is important to her and she feels that it alleviates her level of physical pain, even if sometimes the reception staff at the medical centre make her feel unwelcome through their facial expressions and body language.

Some participants spoke about how the use of language within a health care setting can lead them to feel excluded. Communication and language barriers do not necessarily mean issues with fluency in English, and that this type of exclusion can manifest in a variety of ways. A member of one focus group commented: *“Ms, Mr, X, Other. I don’t believe that Other is appropriate, I don’t believe that X is appropriate either. If you’re a gender-diverse person, then you should have somewhere on that form to put in your title, put in your preferred name, put in what your pronouns are and stuff like that.”* Participants also shared how these experiences took place on multiple occasions in many different places and spaces outside of healthcare settings. Therefore, negative and exclusive experiences in health settings meant health care became one more unsafe space to negotiate or avoid in their daily lives.

Cost

The cost of receiving health care was a key barrier to accessing care for many participants. Having to pay for services upfront or not being aware how much services would cost was of particular concern to some participants when accessing health care. Fifteen interviewees described cost as a barrier to seeking care from GPs, Medical Specialists, dental services and fertility services. Focus group participants also spoke about the cost of services, leading some to avoid seeking care from their GP, dentist, physiotherapists or mental health services: *“I am inclined more to not go to the doctor. I’ll wait until something’s really bad and then I’ll pay for it.”* Another stated: *“I don’t see one [psychologist] because I can’t afford it.”* One focus group member talked about the lack of bulk billing: *“I can’t get into a bulk bill clinic in Shepparton”* and another participant from a small group of young men identified that the cost is more than just the health provider fee:

Sometimes you’ve got to go to Shepp or sometimes you’ve got to go straight to Melbourne about it. It’s just like \$80 there, go there and they send you a bill and after that you go to Melbourne and then you get it fixed. And then you get all these bills piled up. It’s really shitty I guess because it doesn’t really drive you to go anywhere. Just go when you’re about to die I guess.

A few interviewees spoke about feeling that they have little choice when accessing the public system and this is especially the case when requesting a female clinician. Several interviewees described their understanding of the need to pay in order to access good quality care with some also adding that cost was the reason they had private health insurance. In the focus groups, a few participants wanted access to no or low cost transport or wanted service providers to come to them, as they had little access to transport or were too young to drive. Participants’ description of cost as a barrier highlighted that the choice to access health care or to prioritise their health is, at least in part, relative to their ability to afford the service. This is seen by many to be problematic, impacting on the way services are accessed and detracting from participants’ overall health and wellbeing.

Waiting times

A large proportion of participants spoke about the long wait they experienced when accessing acute care. In particular, 28 interviewees identified long waiting times at their local Emergency Department. For example, in the interviews, a few shared their experiences of waiting for hours with their sick and/or asthmatic child, when in acute pain, or when pregnant and experiencing bleeding. Some assumed that this long wait time is due to the lack of facilities (such as the lack of

beds) or doctors. Further, 10 interviewees recalled how no action was taken and they were told to go home and/or see their GP without a satisfactory explanation.

Interviewees discussed instances when they needed to access the local Emergency Department, such as needing immediate care after hours when medical centres are closed, being referred by GPs or pharmacists for what they perceived to be needing urgent care, medical centres not taking new patients, or experiencing acute complications during the postpartum period. A few interviewees described their confusion about the protocols at the Emergency Department and that it was not clear how care is prioritised. The frustration that participants voiced around access to the Emergency Department was mostly based on not understanding how the hospital emergency system works and not being informed of why there is a long wait.

Some interview participants also spoke about how emergency staff discouraged them from using their services, one recalling a staff member saying: *“We have a lot of people sick today. You are almost going to wait more than six hours here,”* and another being questioned rhetorically: *“Why are you here?”* When participants were unable to get an appointment with a GP and it was implied that they were using the Emergency Department inappropriately, respondents were clearly frustrated. Waiting at the Emergency Department was also raised in the small and focus groups: *“I’m not saying they were rude or something like that. They were talking very nicely to us, but the frustrating part was they weren’t coming early and they were busy somewhere else, when you were in pain, so that’s the frustrating part.”* In one of the small groups, it was raised that waiting times could be problematic due to previous negative experiences:

Because every time they were saying they are busy...they are busy with some other emergency cases. Like, we do understand that emergency cases have much priority, but what about the cases you have screwed up before? You should have some priority to them as well. Like, checking out from the hospital after delivery, four days, if anything happens, you can’t go to the hospital directly. You have to go through GP. Why? You should have given 30 or 40 days that within this timeframe, you can come to us, you can come to birthing suite any time within these 30 or 40 days.

Another common issue raised by participants was the associated wait times when booking an appointment with a GP, Specialist or with radiology services. The long wait time for an appointment meant that the level of suffering experienced by participants often increased, especially those experiencing acute pain. This then led participants to seek care from the Emergency Department. In the focus groups, some participants were frustrated with waiting times for surgery, and having to see multiple health professionals when being diagnosed and treated: *“because it’s a hormone imbalance ...it takes so long to get any treatment done. And so you’re still waiting years later.”*

Quality of care

Some participants spoke about the quality of care received. A few interviewees described GPs as not being thorough, culturally appropriate, or not delivering quality care. An LGBTIQ+ focus group discussed their expectations of medical professionals, where three separate participants commented:

I don’t think I have found a GP that fully understands a female sleeping with another female. I don’t think any of the GPs I’ve ever seen fully understand what that is or what it means. I guess you have a level of expectation that your health professional knows how you would be having sex and what you need in terms of like, your care.

I would say too, that unless you're seeing a trans-inclusive doctor, for a trans person, they wouldn't know what you need because you go in there. If you're a trans and on your medical form it says that you're male, but your body is still biologically female, a lot of things get missed or not asked and it becomes this awkward, like, same for the other way around.

Being able to communicate effectively and adequately with a medical professional is vital because we have to self-advocate so much. And it's not sustainable. These are the professionals who are supposed to be educated and knowledgeable and you go to your Specialist who is supposed to focus in a certain area and it's just not enough.

Case Study 3: A young student

Muhammad is a young cisgendered man in his early 20s who was born in Australia to immigrant parents. He has spent most of his life in Shepparton and has decided to move to Melbourne to go to university.

Muhammad tends to not see the doctor, whether it be for a check-up or when he's really sick. This is because in the past he has had negative experiences, where the recommended medications "*don't work*" or the waiting time at the clinic required that he miss a full day at work.

He once went to the Emergency Department when he was ill because all the medical centres in town were either fully booked or not taking new patients. He waited for about three hours and then decided to leave without seeing anyone. He felt guilty being there as he was young and felt there were other much sicker people. He indicated that he was taking a spot in the queue for someone that needed it more than him. Instead, he went home and took a strong painkiller and tried to sleep.

He has a GP that is of a similar cultural background to him, who is known in his community and by his family. In the past when he needed to see his GP, he was not confident that they would keep the information private. This was particularly the case when he needed to get a sexual health check. There were also occasions in the past when the GP did not explain the issues clearly, even though they were both speaking Arabic. Added to this, the GP was always too casual and for most of the part dismissed Muhammad's concerns, telling him "*don't worry about it.*"

Another medical clinic that Muhammad has attended is the local Aboriginal Medical Service. It can be hard to get an appointment but he had always found the environment welcoming and comforting. He said there was always "*someone there to greet you with a smile*" and he felt that the First Nations people working there understood him a bit more. Moreover, the health professionals took their time to understand him and he was not made to feel like "*just another patient.*"

Another place that Muhammad felt welcomed at was a private dental clinic. He felt that the service they provided was professional, the wait time was not long and the waiting room was clean. He would like to get his teeth checked, cleaned and maintained more often but the cost is difficult, especially with going to full time study.

Participants in the focus groups suggested that reliance on information from the Internet by service providers did not instil confidence. Other focus group members had concerns about privacy and confidentiality, relating to discussions that were overheard, knowing others in the waiting room or hearing other conversations through “*thin walls*” in the service. One participant from a small group commented that conversations are easily overheard: “*I had my period and he’s a male doctor. And he wanted to check me out and I said no, I don’t want to be checked out because I, you know, I’ve got my monthly and I heard him talking [to another health professional] that, you know, sometimes people can be stubborn.*”

Some participants recognised that staff are pressured for time and this impacted on their ability to provide appropriate and/or quality care. Examples given included: not assisting with feeding or bathing a hospital patient with a physical disability; health professionals not following through with referrals; and not providing pain relief and then ward staff sternly instructing patients to ask for pain relief earlier. While interviewees were sympathetic to the busy-ness of professionals, some said they felt they, as groups with specific needs, were the patients/clients to receive the least attention or time. Focus group participants also suggested that busy-ness was used to justify long waiting times or poor care, with one describing it as “*unacceptable*” in most other businesses.

Navigating the health system

Interviewees spoke about their experiences navigating the health system. Some said there was a lack of information provided, others felt uncomfortable to ask questions and some suggested there was an expectation by health services that service users know how to access the service, where to go and what would be provided. Three young teens spoke specifically around the laboriousness of the referral process when trying to access Specialist mental health services, such as needing a referral from a GP to access subsidised mental health support, interruption in treatment due to running out of number of subsidised visits as well as the uncertainty and waiting to see if referrals have been processed.

New arrival participants explained that navigating health care in Australia is vastly different to their country of origin. A few described their uncertainty in navigating health care, with some unsure whether their GPs would provide the right information, or not knowing where to go for a particular health problem, being unsure of cost and not knowing what to do to navigate the health care system.

Young people were a particular group who expressed being unsure where, when and how to access services. While some young people relied on family, for others family was not an option and they largely avoided services because they were unsure of where to go, if they needed a referral, what the cost would be, and if their concerns would be considered serious. For the young people that were connected to a service, they relied on receiving information and referrals from the services they used.

Rural living

The issues of living rurally were identified to play a role in the way health care is experienced. Several interviewees discussed the difficulty of having to travel to different areas and/or Melbourne in order to access care. A few interviewees also spoke about their concern around confidentiality in rural areas, as they described an increased likelihood of residents being familiar with one another.

One interviewee gave an example of how a car parked outside a service has the potential to raise questions amongst those familiar to the owner of the car. Lack of transport in rural towns was also seen to be a problem when accessing health care and, for some, trying to align strict appointment times with bus timetables was very challenging.

Case Study 4: A young mother

Katrina is a 20 year old mother with two small children, aged 2 years and a 3 month old baby. Katrina has a supportive partner. They are currently homeless and Katrina is also suffering from mental health illnesses (Post-Natal Depression, Post-traumatic Stress Disorder and Bipolar) of which she is trying to seek treatment. In addition, she has had reproductive health issues and has had to attend the local Emergency Department on a number of occasions in significant pain. She is often asked by staff in the Emergency Department if she is sexually active, assuming that she could be pregnant. However, Katrina identifies as gay and has repeatedly told staff that she is sexually active but could not possibly be pregnant as her current partner is a woman. At this point she says, the staff's body language displays an uncomfortableness and she feels judged.

Katrina's medical records also identify her three mental health illnesses and she has heard staff talking about her at the nurse's desk, warning each other to be careful around her because of these "mental health problems". This makes Katrina feel upset and ashamed because she has attended the Emergency Department due to her pain that is unrelated to her mental health. Moreover, she is trying to seek treatment for her mental health illnesses, albeit unsuccessfully. She is linked with Acute Mental Health and Perinatal Emotional Health. She receives a phone call each week from Acute Mental Health as a way for the service to check in on her but when she tells them she is homeless, the health professional tells her that they are unable to help her and she feels left to deal with these issues. She has received some support from the perinatal service but they are unable to help her receive treatment for her mental health illnesses. Other local mental health services have told her that they are unable to help her. She has been on a waiting list with a homelessness service for many months and is extremely anxious that child protection service may take her children away. Her mental health illnesses continue to deteriorate as she sees no end and no help in sight. She feels rejected by the health system; while service providers listen, no professional will assist with the homelessness.

Impacts of negative experiences

For those with negative experiences of accessing health care, it was described as leading them to avoid seeking care or delaying seeking care. A focus group of young people described how disrespectful interactions led themselves and family members to not want to use a service. Another participant from this group (with an advocacy role) explained that the "*behaviour towards*

her clients, towards the patients, used to turn off, like my mum and the other ladies that I take. They don't go anymore. They're like 'we'd rather be in pain, rather than go see her'."

In one case, such interactions lead to service use being replaced by increased medication use. A few interviewees spoke about how one negative experience led to them avoiding using services while 10 participants admitted to only seeking health care for acute needs. Three First Nations interviewees talked about how they avoided seeking care due to the lack of cultural knowledge, understanding and assumption-making currently present in health services. Two First Nation interviewees described how stories of exclusion faced by their Elders in the past has had a huge impact in the way they currently use health services. Another interviewee described the avoidance of seeking health care as pertaining to feeling *"the pain or discomfort because we are sick, I think for me behind all of that, the reason is just I'm scared."* For an LGBTIQ+ focus group member, one comment heard at a health centre led to ruining the rest of the day, indicating the compounding impact of judgements and comments about an individual's identity. After hearing the comment, the person described:

And that kind of did my head in for the rest of the day. We went to go somewhere else and, oh no, I don't feel like going. This person has referred to me as a girl or a woman or whatever before. I don't feel like dealing with that today, I've already dealt with that. Once a day is more than enough for anybody.

Case Study 5: From one bad experience to the next

Greg is semi-retired and receives a partial pension, although not by choice. He suffers from chronic back pain from a work injury and is unable to work full-time. He does not like to see health professionals for treatment as he *"always"* has bad experiences. Greg has had disappointing and frustrating consultations with GPs, Specialists and allied health professionals in the past who have been unable to effectively treat his back pain. Now when he is unwell, he tends to wait to see if he gets better or worse before seeking care. He is used to being in pain and says *"having a few glasses of spirits each night"* helps to ease his pain and that without it, he would not be able to rest, lie down or sleep.

Along with living with his chronic back pain, Greg also suffers from anxiety. He has been referred to several psychologists but found none of their suggestions worked for him. One suggested he try an online mindfulness course which he found unhelpful and made his anxiety worse. The course required him to focus on his breathing which he found made him struggle to breathe, leading to panic attacks. Another psychologist suggested group therapy and although the group made him feel that he was not alone, it did not ease his anxiety.

On one occasion, Greg felt unwell and dizzy. Unable to get an appointment with his regular GP, he consulted a GP he was unfamiliar with. The new GP suspected that Greg had suffered a heart attack and sent him to the Emergency Department. Upon attending the Emergency Department at the local hospital, Greg was told that because it was the weekend, there were no Specialists that could attend to him. He was given blood thinners and sent home. The whole experience made him anxious and when he tried to make an appointment to see his regular GP, he was told that his GP was fully booked for the next week and a half. He described how moments like these make him despondent and question *"what's the point of going to see someone? It's just not a good experience."*

Ways health services can improve

Participants were asked for suggestions on ways that health services can improve and provide quality care. Almost half of all participants articulated ways that interactions and communication between health professionals and patients/clients can be improved. These include:

- Being welcoming in body language (e.g., smiling, engaging in small talk, body language, facing the patient/client rather than the computer/interpreter/parent)
- To not make assumptions about a patient/client's identity, culture, preference or health issue
- To communicate in ways that reflect the practitioner seeing the patient/client in human ways with varying capacities and needs
- Showing care, transparency of the health processes and thoroughness
- Taking the time to listen to patient/client's concerns
- Being respectful and free of judgement, regardless of patient/client views
- Communicating waiting times, cost and other service protocols for patients/clients in order to manage expectations

Further, building and maintaining trust and rapport were considered quite important among participants. One First Nation participant suggested looking towards and learning from NAIDOC events which often have strong engagement with Traditional Owners and local First Nations peoples.

Some participants also emphasised the need for health professionals to be adequately trained in areas such as:

- Training on communicating, listening and exercising patience
- Training on First Nations culture, re-learning the real history of Australia and linking it with the underlying issues of health disparities and impacts of colonisation
- Training on supporting clients experiencing mental health issues
- Training on supporting clients experiencing Family Violence
- Training on issues faced by people who identify as LGBTIQ+ and for services to undergo the Rainbow-tick process

One participant spoke about the importance of not simply offering the training but that health services need to ensure that their staff complete the training. Moreover, this interviewee suggested that changes taking place within organisations must be embedded in the policies and culture of the health service.

As previously indicated, some participants commented that they do not have a good understanding of the type of services that health organisations offer. One young person suggested that organisations run community events to promote their programs and services. Another interviewee suggested organisations could promote their services by putting flyers in multiple languages in residents' letterboxes or by visiting places where people gather such as community houses, mosques and temples. A First Nation participant added that any promotional materials should incorporate an Acknowledgement of Country and another First Nation interviewee also commented that televisions

in waiting rooms of health services could be used to promote services for various groups of people in a variety of languages.

Other suggestions made by participants include:

- Diversifying the workforce in health care settings (whether it be clinical, administrative or customer service roles)
- Health services organising the required language/disability interpreters and avoid using family members to translate and interpret for a patient/client
- Increasing bulkbilling services (including bulkbilling mental health services)
- Displaying First Nations flags and local First Nations' artworks in health services
- Reviewing how appointments are scheduled so that adequate time can be spent with a patient/client
- Prioritising First Nations Elders when they attend Emergency Departments
- Prioritising the cultural safety of the health service environment for First Nations people
- Health services offering programs with outreach services that are affordable and accessible (e.g. flexible times, including before and after business/school hours or weekends)
- Streamline referral processes so that access to services is clear to service users as well as efficient and prompt
- Designing health services in ways that are inviting, welcoming and private
- More funding for public hospitals
- More health professionals in rural areas so that more appointments are available for residents
- Create an easy, flexible and accessible complaint process

Conclusion

This report describes the complexity of experiences of using and going into health services for residents of Shepparton. These residents' experiences are a combination of simultaneously positive and negative stories, with the majority of participants describing health services as generally "good." Many are appreciative of the availability of services but also suggested ways that health services could improve so that they are more accessible for everyone. Exclusionary practices occur in various ways and this report has demonstrated that people of all backgrounds can, and have, experienced these in health services as well as in other arenas. Along with the recommendations on ways health services can improve, the stories shared by these participants highlight six key messages:

- (vii) Avoid making assumptions about patients/clients and their needs or preferences based on obvious identities and/or social and physical factors
- (viii) Practice in ways that are genuine, caring and compassionate
- (ix) Provide information about the service, its availability, cost and how to access the service

- (x) Listen to, respect and act on patient/client requests where possible, even if they are not considered the priority for the health professional
- (xi) Tailor care for individual patients/clients and their families
- (xii) Acknowledge that patients/clients are unwell, may be stressed, may be intimidated and may have had past negative experiences with other services

The study highlights that service users have different experiences and expectations from health services. This study found that health services in Shepparton of all types provide inclusive and appropriate care for many participants, however there are also local residents who experience a lack of inclusion, safety and respect when using health and other services. The compounding impact of navigating services in conjunction with disempowerment experienced through exclusionary practices leads to disengagement with health services, both currently and in the future. Therefore, this study advocates that health services and professionals are always welcoming, respectful and responsive, without judgement or assumption.

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