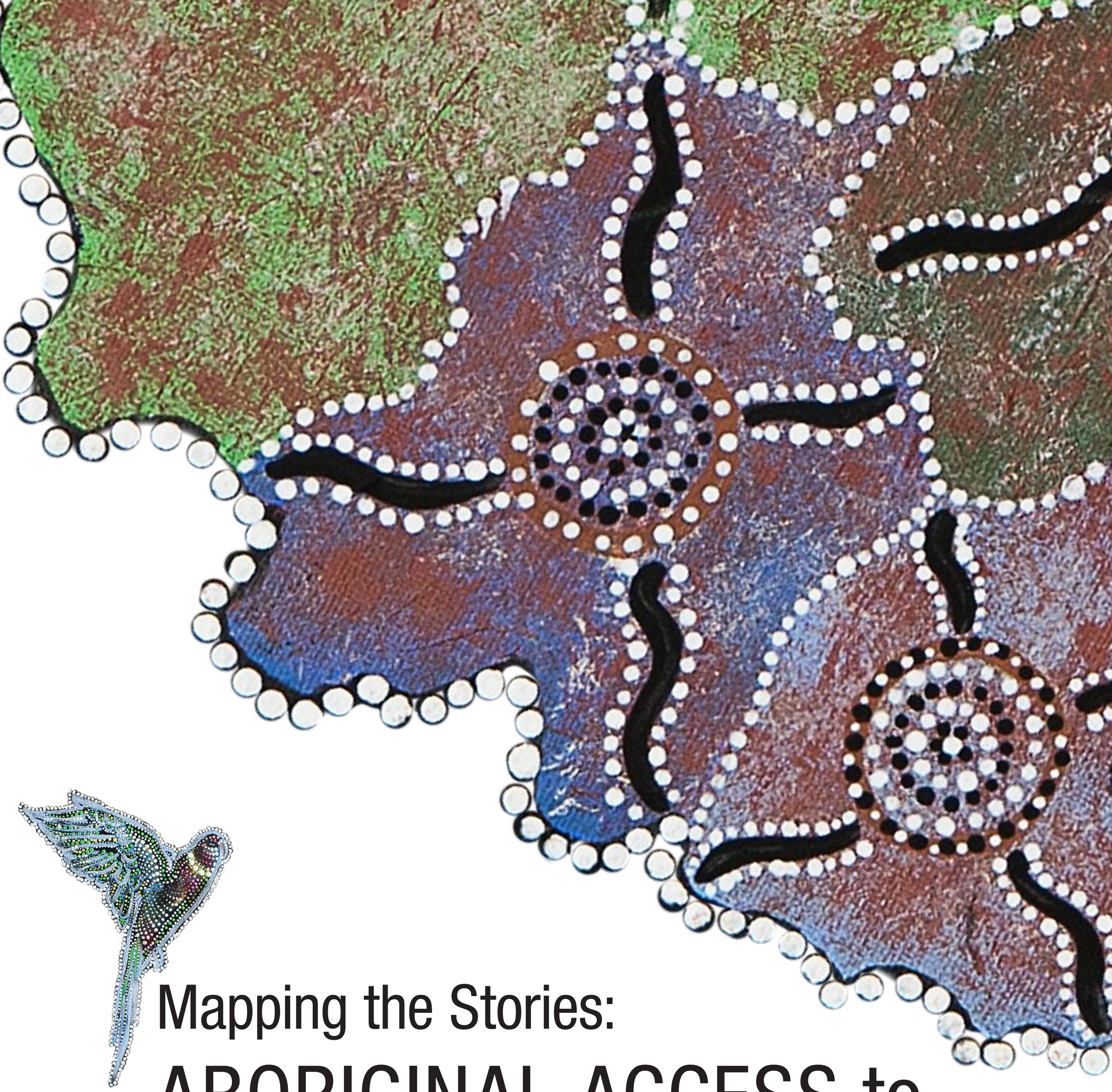

# Mapping the Stories:

# ABORIGINAL ACCESS to SERVICES in the NEPEAN BLUE MOUNTAINS REGION

SYNERGIA

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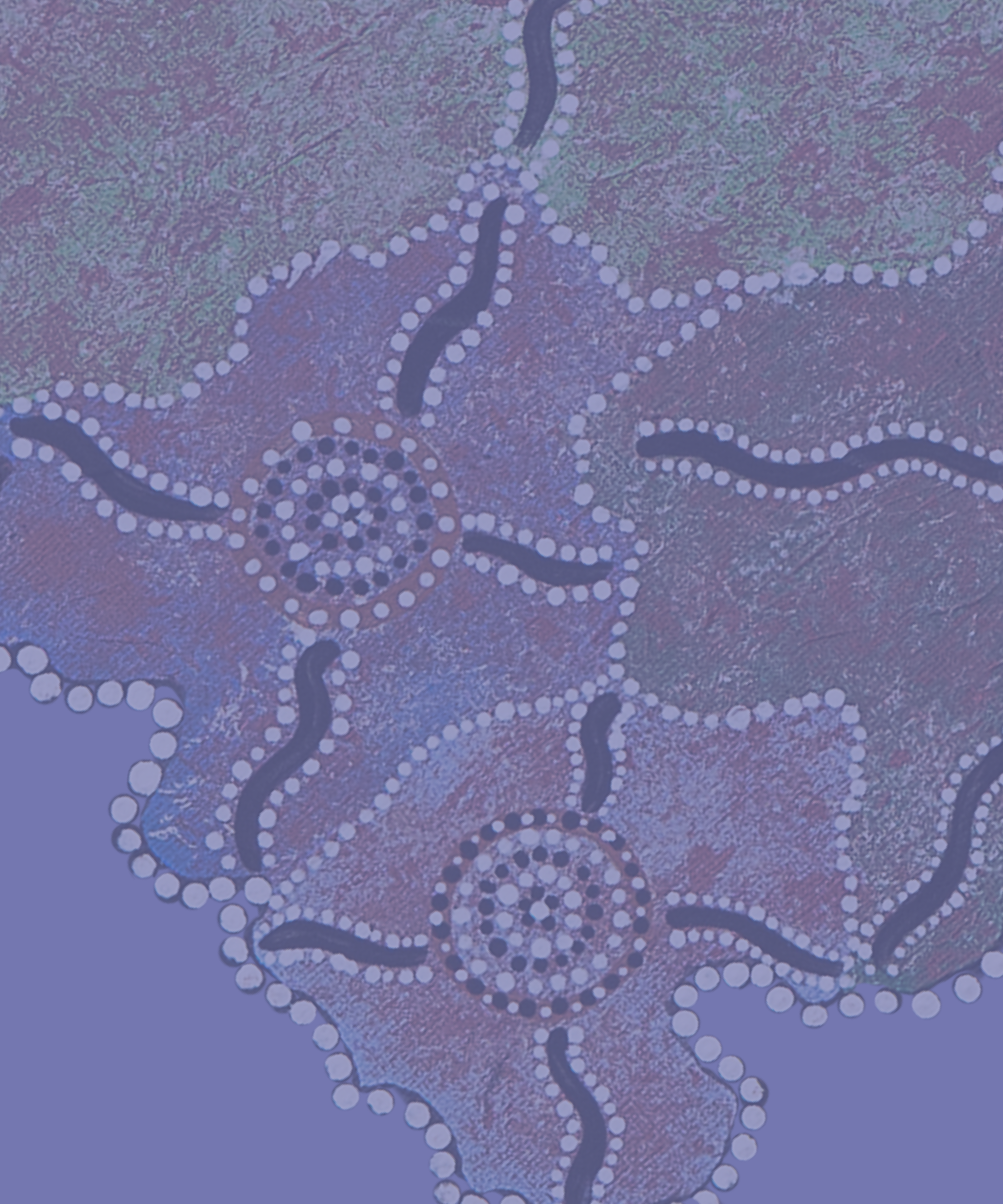

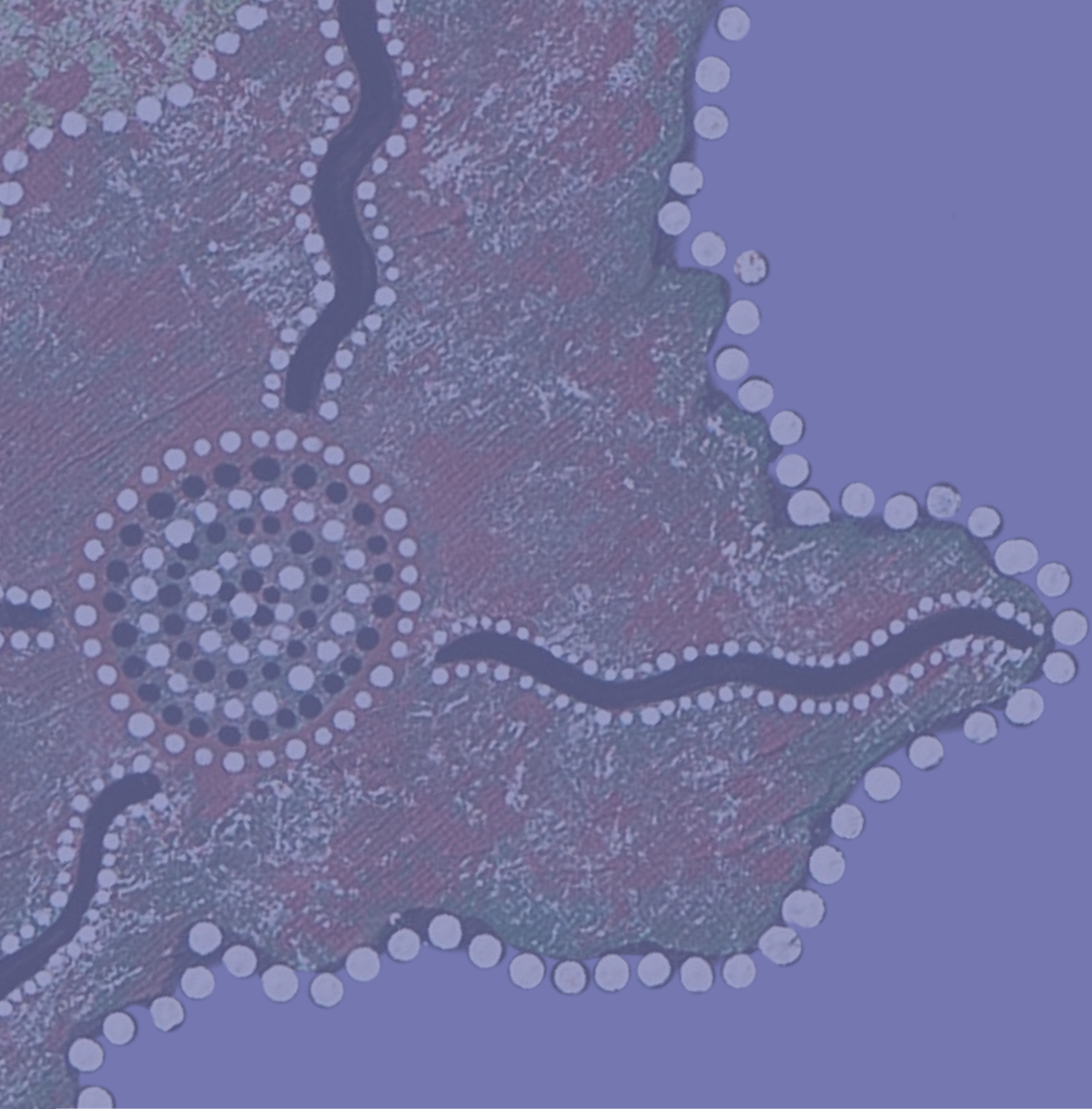

**We acknowledge the traditional custodians of the lands on which we work and pay our respect to Aboriginal Elders, past and present.**

**The Dharug, Gundungurra and Wiradjuri people are acknowledged as the traditional owners of the land in our region.**

This artwork is a section from a painting created by local Aboriginal Artist Vicki Thom specifically for our Reconciliation Action Plan. It depicts the relationship between local Aboriginal people and how they interact with the land and the PHN, describing the journey to understanding each other.

ACKNOWLEDGEMENTS

This report was commissioned by Wentworth Healthcare and prepared by Dr David Rees, Zaffar Ansari and Amy Levenberg from Synergia, 14 January 2021. **www.synergia.co.au**

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# CONTENTS

# 1. BACKGROUND

Despite ongoing attempts in the health sector to improve the health outcomes of Aboriginal and Torres Strait Islander people[1], the gap remains (The Lowitja Institute, 2019). Aboriginal People across Australia are over-represented in ill-health statistics, including a higher prevalence of physical health issues like type 2 diabetes, renal disease, cardiovascular disease, eye disease (Australian Institute of Health and Welfare, 2018), mental health (Australian Institute of Health and Welfare, 2014) and infectious diseases such as rheumatic fever and skin infections (Australian Insitute of Health and Welfare, 2019). This is a narrative that we have been hearing throughout the “closing the gap” campaign and with the priorities from the State and Federal governments, but significant change has yet to be seen (The Lowitja Institute, 2019).

To improve these outcomes it is important to understand what is driving them. This research aims to contribute to that understanding by sharing the stories of a group of Aboriginal People and their experiences of accessing health services and the services provided when they are accessed.

This report, based on 19 interviews and a follow-up workshop with those interviewed, uses case stories to describe the journeys Aboriginal People, from Nepean, Blue Mountains, Hawkesbury and Lithgow, make interacting with the health system in the Nepean Blue Mountains Region. It then uses these stories to describe opportunities for improving the health system and services by making them more responsive to the needs of Aboriginal People. By better understanding the needs of Aboriginal People, it may also contribute to building the capacity of the broader system to develop supports that are culturally safe and accessible.

The most important goal in this research is to understand these journeys through the eyes of Aboriginal People, giving them a voice and the opportunity to tell their story. This research recognises that Aboriginal People have experienced, and continue to experience, various types and levels of trauma, including intergenerational trauma due to the ongoing impact of colonisation and horrific historic legislations that led to cultural injustices like the Stolen Generations. Hence, it was important that the research was designed for, led by, and implemented with, Aboriginal People. It has sought to empower people to share their experiences, including positive and adverse experiences, that will contribute to a collection of stories for the health care system to hear and to understand. The information included in this report details the unique journeys, experiences and beliefs prior to, during and after engaging with health providers and facilities. It aims to capture an understanding of the inherent challenges and barriers faced by Aboriginal People in a western clinical system and highlight how the health sector can best change to support the needs of an already vulnerable population.

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[1] For the purpose of this report, Aboriginal and Torres Strait Islander people will hereafter be referred to as “Aboriginal People”

Writing across cultures can be difficult, with many opportunities for misinterpretation, not least in the use of the term 'Indigenous' or 'Aboriginal'. They are words that imply a degree of homogeneity that hides the enormous diversity in Aboriginal Peoples, Torres Strait Islander Peoples and their cultures. The word 'Aboriginal' is a term that was not used prior to the arrival of Europeans. In Australia, people identify themselves by their nation, their country, their mob and not the larger group Europeans refer to as Aboriginal.

So, while throughout this report we refer to 'Aboriginal Peoples' we are acutely aware that, despite much that connects them, the people we interviewed are a diverse group from different nations and cultures.

This research presents the stories of 19 Aboriginal People in the Nepean Blue Mountains, Hawkesbury and Lithgow regions. It is therefore their stories, and it is important to note that it cannot and is not representative of all Aboriginal People. Individual experiences are unique by nature. As such, a limitation of our research is that the experiences captured represent only a small window into the challenges and issues faced by Aboriginal communities. But this should not detract from the importance of the stories presented below that we have been privileged to hear. Empowering people to tell their stories and have their voices heard is invaluable and provides health providers with useful context for the issues and challenges currently embedded in the system and with these in mind, begin a conversation about the opportunity to collectively design potential solutions.

## 2. THE DETERMINANTS OF HEALTH: ABORIGINAL PERSPECTIVES

Aboriginal and Torres Strait Islander Peoples are representatives of the oldest surviving, living culture in the world. It is a culture with a rich, longstanding history and is underpinned by complex and uniquely developed systems of governance, laws and health, shaped by their understanding of the world and the experiences of their ancestors who came before them (Funston, 2013). Utilising research and the current experiences of Aboriginal Peoples is important when informing change. However, it is also important to ensure that findings are analysed and presented through an Aboriginal worldview. This provides a cultural lens through which we can better understand the context of the Peoples' stories and how Aboriginal cultures lend themselves to different perspectives of health and how this may be prioritised.

A cultural worldview provides a lens through which to frame issues. It identifies and highlights important cultural values that influence the way people live their lives. For Aboriginal communities, the cultural determinants of health largely focus on the social and emotional wellbeing ('SEWB') of the whole community. (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014)

> "Aboriginal health means not just the physical wellbeing of an individual, but refers to the social, emotional, and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life." (National Aboriginal Health Strategy Working Party, 1989)

The SEWB model, shown below in Figure 1, shows the interconnected domains of an individual's life. It takes the view that the self, seen in the centre of the model, is "grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community" (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014). From an Aboriginal perspective, when you are interacting with an individual you are also, in a very real sense, interacting with their family and community. Viewing health through this lens provides an insight into Aboriginal beliefs, and the multiple factors that continuously, and sometime subconsciously, impact on health decisions.

For Aboriginal Peoples, 'good health' is all encompassing. It does not only refer to the absence of disease, but instead speaks to a state of holistic wellbeing (Ganesharajah, 2009). The physical, social, emotional, cultural, spiritual and ecological factors are interconnected and they all play an important role in the wellbeing of an individual (Australia Institute of Health and Welfare, 2019). This means that for Aboriginal Peoples, factors such as social order, ritualistic and traditional healing practices, connection to land and earth are inextricably linked to wellbeing and illness (Vass, Mitchell, & Dhurrkay, 2011). The concept of 'patient-centred' care has different boundaries when looked at from an Aboriginal perspective.

**Figure 1: A model of social and emotional wellbeing**[2]

Reflecting on previous research, and literature about what it means to be healthy in Aboriginal cultures is an important component of this work. Without it, there may be parts of the stories that could be overlooked by others who don't identify as Aboriginal. By understanding these domains, we can capture the nuances that are culturally relevant and critically important, using them to add value to a collective and complex issue. When analysing the data, having an Aboriginal worldview at the forefront of our minds helps to uncover these culturally specific issues and helps influence change in a system that often disregards their importance when making decisions.

It is important to note however, that there is huge cultural diversity within Aboriginal culture, which means that the value of each of these domains and their relevance will differ from community to community. Similarly, the domains within the SEWB model do not exist in siloes, they have been separated for the purpose of illustrating them to help health practitioners understand how to approach working in the health field (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014).

The rest of this section will unpack a few of the domains represented in the SEWB model and identify the connection they have to the ongoing health of an Aboriginal person.

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[2] Diagram taken from Gee, Dudgeon, Schultz, Hart, & Kelly, 2014

## 2.1 Country, Spirit, Spirituality and Ancestors

Spirituality is the connection Aboriginal Peoples have with the traditions and knowledge that has been passed on from their ancestors. The cultural beliefs are often tied to stories, ceremonies and traditional practices that connect them with the rich history of their land. Thus, the existence of a fundamental link between spirituality and land is clear.

For many, belonging to a certain territory did not only mean being part of that community, but being guided by and connected to the spiritual history of the Ancestors that once travelled across it (Dudgeon, Wright, Paradies, Garvey, & Walker, 2014). The connection to land and country and the sacred nature of the earth is one with rich spiritual meaning. It is not just a physical environment and it therefore, forms an integral part of a holistic view of health and wellbeing (Commonwealth of Australia, 2013, Ganesharajah, 2009). Aboriginal Peoples find solace in their connection to land and their relationship with all things nature, and there remains a desire to be connected, or in many cases, re-connected with it.

> “Our ontological relationship to land, the ways that country is constitutive of us, and therefore the inalienable nature of our relation to land, marks a radical, indeed incommensurable, difference between us and the non-Indigenous” (Moreton-Robinson, Ahmed, Castaneda, Fortier, & Sheller, 2003)

## 2.2 Family and Kinship

A holistic approach is seen through an Aboriginal person’s connection to their family and community. A person’s health and wellbeing intertwines with the health and wellbeing of their immediate and extended family and their wider community (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014). It is not uncommon that Aboriginal Peoples’ perception of their health is dependent on the health of their children, parents, grandchildren, extended family and broader community. Thus, the focus of wellbeing for Aboriginal Peoples is often more about ‘we’ than about ‘I’.

Linked to this is the kinship system, which forms the infrastructure upon which Aboriginal communities are based (Aboriginal Services Branch, 2009). It is a complex system and starkly different to a non-Indigenous system. Kinship networks overlap and are fluid, they push the boundaries of the Anglo-centric meaning of ‘family’. So much so that the meaning of family in a Western context does not reflect what it means to many Aboriginal Peoples. In an attempt to reframe this, Families Australia defined family as “what people define them to be” (Robinson & Parker, 2008) and for Aboriginal Peoples especially, there is huge value placed on social relationships and collective responses.

Collectivism is also connected to the idea of reciprocity. In Aboriginal cultures, sharing resources, giving back to the community and being aware of the needs of others takes precedent (Walker & Shepherd, 2008). As mentioned before, wellbeing is dependent on the collective health of a community.

## 2.3 Culture

The term culture is a complex one. As we have already mentioned, even when talking about Aboriginal culture, the amount of variation and diversity is vast. However, that does not detract from the fact that a strong cultural identity and connection is important to building resilience and obtaining 'good health'. This means that Aboriginal Peoples must have the "capacity and opportunity to sustain and (re) create a healthy, strong relationship to their Aboriginal and Torres Strait Islander heritage…to maintain a secure sense of cultural identity and cultural values, and to participate in cultural practices that allow them to exercise their cultural rights and responsibilities" (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014, p.61)

Cultural practices and protocols are a part of this. There are roles and expectations within Aboriginal cultures that can impact on health outcomes and the willingness to seek help. Cultural protocols around men's and women's 'business' result in some health and other community activities being most appropriately managed and prescribed independently of the other gender. (Aboriginal Services Branch, 2009). This can therefore impact greatly on how, when and why health services are accessed and delivered by Aboriginal Peoples. On the same note, for some Aboriginal Peoples, there are topics which they feel more comfortable talking to another Aboriginal person about. This highlights the need for an Aboriginal workforce to ensure this does not continue to be or become a barrier to access for Aboriginal Peoples.

Finally, there are also particular roles within the family system that are tied to cultural identity (Aboriginal Health Council of South Australia, 2019). For example, recent research from the Aboriginal Health Council of South Australia suggest that influence in the family is important for women, but not as much for men. This reflects the idea that for many Aboriginal Peoples, women are still seen as the glue that keeps the unit running, and this too can impact on how women define their health needs and access health care.

Being connected to culture has been shown to improve resilience and personal strength, it is a protective factor against physical and mental illness (Calma, Dudgeon, & Bray, 2017) and this needs to permeate through the current health services available.

## 2.4 Determinants

It is important to understand the context in which the SEWB rests. Represented in Figure 1, on the outer edges, are the social, historical and political determinants that must be considered as they cut across these cultural needs. Social determinants refer to issues of poverty, housing, education and employment, discrimination, exposure to violence and access to resources. Historical determinants, specifically added to the SEWB due to the uniquely horrific experiences of Aboriginal Peoples, refer to the oppression and displacement caused by colonisation and past policies. Finally, political determinants refer to the on-going impact of colonisation in relation to issues of land ownership, cultural security and the rights of self-determination (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014).

In order to work with Aboriginal Peoples and to understand and unpack layers of trauma caused by these policies and intergenerational inequities, health providers need to have basic knowledge of the history of the Indigenous community.

## 2.5 Conclusion

Despite discussion since the 1970s, the current approach to healthcare here in Australia, underpinned by a biomedical model, fails to prioritise holistic health and implement such ideas into practice (Closing the Gap Clearinghouse, 2013; Lutschini, 2005). It is a system that presents barriers for Aboriginal consumers. Studies have shown high rates of discrimination, racism and marginalisation continue to permeate health services (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Paradies, et al., 2015; Cunningham & Paradies, 2013). Further, a lack of culturally appropriate services and communication by health workers compounds the issue (Aspin, Brown, Jowsey, Yen, & Leeder, 2012). The inability of health workers to recognise, acknowledge and understand culture, of any kind, needs to be addressed (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Amery, 2017).

The gathering of Aboriginal perspectives and healthcare needs, including culturally defined and holistic notions of ‘wellbeing’, will contribute to healthcare providers gaining knowledge and building an understanding of what these are. It will help to inform change and to re-create a health system that recognises the importance of cultural diversity and traditional needs.

> “Our identity as human beings remains tied to our land, to our cultural practices, our systems of authority and social control, our intellectual traditions, our concepts of spirituality, and to our systems of resource ownership and exchange. Destroy this relationship and you damage – sometimes irrevocably – individual human beings and their health” (Anderson, 1996)

The Nepean Blue Mountains region is made up of a diverse group of Aboriginal and Torres Strait Islander Peoples. The health region itself crosses a number of Aboriginal Countries, including Darug, Wiradjuri and Gundungurra Countries. Aboriginal and Torres Strait Islander Peoples living in the region may come from various other Countries and make up a culturally rich and diverse community. Understanding and harnessing this diversity to develop approaches that empower and improve outcomes for Aboriginal and Torres Strait Islander Peoples is fundamental to the work of health and social services and systems. Recognising the power of collective experiences as well as respecting individual and unique perspectives is a challenge and can be hard to balance. However, it is also presents an important opportunity in the planning, design and delivery of effective services throughout the region.

# 3. INTERACTING WITH THE HEALTH SYSTEM

The approach we have taken in the interviews starts from the viewpoint that people are seekers of wellbeing, and that what constitutes wellbeing will differ from person to person, affected by factors such as their social and cultural context, their age, their gender. This viewpoint emphasises Aboriginal Peoples as self-determining participants in the relationship, not as passive consumers of what is presented by someone else. As noted above, identifying as Aboriginal brings with it perspectives and relationships that are fundamental to wellbeing and what each person, provider and patient, brings to the interaction and how the broader system responds to it, will affect how it works.

This 'people seeking wellbeing' perspective highlights that health interactions must be based on supporting people in the context of their own lives, and not just as patients. Their interaction with the health system is only one aspect of their wellbeing, a continuous process of taking steps towards better physical, emotional and spiritual health (Jones, 2013). Health-seeking is different for each person. For some, health-seeking is becoming fit enough to run a marathon. For others it is being able to walk to the shops, being able to spend time with family. For some it maybe surviving treatment or fighting to regain function after a significant event. For others, it is being able to carry out the core activities of daily living. Furthermore, people must be seen in the broader context of their life journey. At times they are caregivers. At other times they are patients, and sometimes they are both. Health providers, and the system more broadly, needs to understand and respond to this context holistically if they are to deliver appropriate services.

## 3.1 The Life Journey: Seeking Wellbeing

For much of their lives, people's health journey takes place in a family and community context, with no connections to the health system. They get their information from a wide range of sources including family and friends, their Country, culture and community, and consumer health services. Their key interactions are at home, with family, school and work, with some people also connecting strongly through social media. For many people, the prime focus is on the health of their family and friends. It is also a focus not just on physical health but on holistic social and emotional wellbeing (incorporating physical, social, cultural, emotional and spiritual wellbeing).

When a health concern arises, sometimes suddenly, often over months, and sometimes years, the person will often become more focused on their personal health, confiding in a smaller circle of friends and family. Their focus is on their personal health and wellbeing, and their ability to sustain their personal level of functioning, including the roles they play in their family and community.

At some point, this concern increases to the point where the person seeks a diagnosis, usually with a health professional, but sometimes with a traditional healer, friend, or even from the internet. A major focus for the person at this point is understanding the diagnosis and its implications for their life, hoping, at least initially, that they will be able to recover to their previous level of functioning. When traditional healing practices are involved, the person may also have to contend with differing and sometimes conflicting views of what the cause of their ill-health is and what to do about it. As time goes on, and treatment begins, the person develops a small set of new relationships, in which those providing the health services now take on a more prominent role. Furthermore, as the reality of their condition becomes apparent, restoring health to previous levels of functioning may no longer be possible, so the focus shifts to the best health outcome possible. As treatment continues the focus goes on to coping with the consequences of their conditions and learning to live well within the constraints that it may bring. At some point the focus shifts back to their family, seeking health and wellbeing for the family they are part of.

### 3.1.1 Mapping the Journey

In mapping the journey it is important that we capture the interactions that take place along the journey, describing not just what happened but also what the person wanted to happen and what they wanted to know.

For example, early on, following a ‘health event’, and starting to seek out a service a person often wants to know:

- What is my condition and how will it affect me?
- What are the processes involved in potential tests and treatments?
- What are my options?
- Where can I go to find out more?
- What do I need to do next?

When initially interacting with a service provider people will often have unexpressed needs such as:

- I want help to make my own decisions.
- I want to be connected to the right services and programmes.
- I need to trust you before I’ll fully engage.
- I need you to trust me.
- I want others to understand.

These are all important things that people want to know and to achieve along the journey and understanding these is crucial if their voice is to be heard.

To guide the interviews we produced templates that provided guidance for the interviewers and scribes. These templates provide a set of questions that help the interviewer to focus on key aspects of the patient journey noted above. They are shown in appendix 1

# 4. ABORIGINAL VOICES: SHARED EXPERIENCES

What follows is a series of stories, either of individuals or an amalgamation of similar individual stories. We have grouped these stories into three main themes, which align to the nine guiding principles that underpin social and emotional wellbeing in Aboriginal culture (Swan P and Raphael B, 1995).

These three areas are:

1. **Relationships**: In many Aboriginal cultures, relationships and connection to others is crucial to holistic wellbeing. This section will look at the impact of relationships in three sub-areas. First, an individual's relationship with their health provider. Second, their relationship with their family, community and kinship and third, the relationship with the broader health sector.
2. **Cultural marginalisation**: This section is multi-layered. From a political and historical context, it acknowledges the past, and sometimes on-going, traumas that many Aboriginal Peoples have been subjected to. This includes the impact of colonisation, the Stolen Generation and a Eurocentric policy-making system. It also highlights the ongoing issues associated with cultural stereotyping – whether this be from a place of racism or ignorance, and highlights the impact of stigma when accessing services.
3. **Self-determination**: Self-determination encapsulates both the right to make decisions about one's health, and have the information, education and knowledge to have the capacity to make that decision. It also alludes to a more political factor which is the right to retain self-determination in an environment and a culture that has been subject to extreme historical and political atrocities. This means being able to access services that help restore and retain cultural values, principals and traditions, not just services that align with the Western medicine model.

It is important to note that the stories that we have shared below do not fit exclusively into one of these three areas. There are overriding determinants that connect all three and the decision to place them in a specific area reflect their dominant theme.

## 4.1 Relationships

The theme of relationships reflects three key stories; relationships with staff, access to resources, communication, and care and compassion. Relationships with staff reflects both the current ways in which the system is working well through culturally responsive staff and also working poorly through poor communication. Access to resources highlights the ways in which assistance to access resources, clinical and non-clinical, is not always provided. Communication focuses on the information that was, or was not, provided during the interaction, while care and compassion focuses on the nature of that interaction.

### 4.1.1 Aboriginal staff

Many interviewees talked about the value of seeing Aboriginal Peoples involved in the care process. This was not only clinicians, but extended to other carers and Aboriginal Liaison Officers. They felt they could trust Aboriginal staff and knew that they would be able to relate and communicate with them.

*"The Aboriginal Liaison Officer made the experience better; it was like having a friend there and it helps to see an Aboriginal face."*

Moreover, some interviewees commented that Aboriginality of staff while ideal was not essential. They talked about positive experiences they had with staff of other nationalities who had strong understandings of Aboriginal cultures and knew how to be culturally responsive.

*"We need more clinicians who understand Aboriginal People"*

This experience highlights the need to remain connected to Aboriginal cultures. The inclusion of Aboriginal health workers serves as cultural brokerage for consumers by helping to reduce the anxiety many experience when accessing services, and by facilitating culturally appropriate communication that aligns with differing levels of health literacy (Bird & Henderson, 2005). More broadly, Aboriginal health workers play a pivotal role in helping the wider system better understand Aboriginal Peoples' needs and concerns. However, this is not to say that skills and awareness pertaining to culture should be solely the responsibility of Aboriginal Health Workers. It is well understood that this responsibility must be shared between Indigenous and non-Indigenous workers (Bretherton, 2014).

### 4.1.2 Accessing resources

Many interviewees discussed the importance of financial assistance. A common theme was worries about their ability to pay for medication and services. *Closing the Gap* was regularly discussed by interviewees as being valuable not only for the financial assistance but also for supporting communication and organisation of healthcare. In relation to cost, several individuals discussed how *Closing the Gap* supported medication costs, purchase of medical devices and transport to appointments.

Some interviewees discussed that they were unsure what sorts of assistance they could get. Interviewees reported that they didn't feel like they were made fully aware of what assistance and services were available to them. One participant commented they had to find everything out for themselves, without the support and guidance from the system.

*"I didn't know where to go, I had to do it all on my own"*

Of those who were able to access assistance, some individuals exhibited caution, feeling a sense of guilt for using services they felt were for people in greater need.

*"I felt guilty for accepting Aboriginal services, there are people who need it more"*

Workshop attendees commented that there is a preconceived perception from "mainstream" people that Aboriginal Peoples get "everything" handed to them for free. However, they do not feel that is the case. Not only do the intricacies and complexity of the system makes it hard to understand what is available, but many of the participants felt that they shouldn't utilise the subsidised or available services because other people in their community are more in need.

For example, when a woman at the workshop talked about the transport issues she has getting to the AMS from one location to another where there is access to a Female Aboriginal Doctor, another of the women said, "what about the taxi card service", a prepaid taxi card from the government to be used for medical appointments. The woman responded by saying "nah, that's a waste of money".

Further, when receiving remuneration for their time at the workshop, in the form of a $50 voucher, one of the men, despite equal need and previously identified health concerns, gave his voucher to one of the Aunties.

*"Yeah I could use it, but she needs it more than me".*

This attitude is not uncommon with Aboriginal Peoples and emphasises the importance of collectivism and reciprocity.

*"He says I have no financial IQ but I'm not silly, I just don't care about money. If I have money, there's always someone or something that needs it"*

Through a complex social network and kinship, acts of reciprocity maintain equilibrium, recognising that as a member of this community, individuals are responsible for the connections with each other (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014). Consequently, what is seen from the experiences noted above, is that this can negatively impact access to health. This does not reflect a person's lack of concern about their own health outcomes, but reflects their attempt to balance their own individual needs, with those of their family and community. For a system that is so strongly focused on 'individualised care' this is a challenging idea to respond to.

### 4.1.3 Communication

Several interviewees mentioned that their first engagement with health services left them with not enough information and many questions about the care process. A common narrative was individuals being uninformed by clinicians about the purpose of their medications, how they work and their effects. They wanted to know more about their medication in general but specifically about what the medication is doing to make them better. Several interviewees discussed how they were unsure why they were being asked to do further tests. The lack of information made them feel uncertain in their care journeys and fearful of what might happen.

*"Why do I need to take so much medication…what does it all do?"*

While perspectives are changing, and a broader conception of health is emerging amongst health professionals, ill health is still largely seen as a problem in the body. It can be fixed with medication and the doctor will determine what medication you should take. While not ignoring the enormous benefits of medication, Aboriginal conceptions of ‘health’ are broader. It is not that Aboriginal People do not see the importance of the body, but see it as just one aspect that needs to be considered. The SEWB model, discussed previously, highlights that the medical model will, at times, be too narrow. The connection to mind, emotion, spirit and body that underpins part of wellbeing requires the discussion about health problems to go deeper than simply knowing the medication will help.

*“I hate taking all these medications. Sometimes I just stop, have a break, if I can. Mentally and spiritually, I try to heal that way too. I ask the ancestors for help all the time. It definitely helps me a lot.”*

Three other issues emerged as impacting the quality of communication taking place. Firstly, some interviewees mentioned that they felt some clinicians used overly technical language and did not make enough of an effort to ensure they understood what was being said. Secondly, there was the issue of gender playing a key role in facilitating communication between clinicians and patients, through the concept of ‘men’s business’ and ‘women’s business’. This reflects a common belief for many Aboriginal People that certain things should only be discussed with people of the same gender. Attached to this idea was discussion about how men often struggled to talk about their health, mental health in particular.

Lastly, interviewees talked about how they didn’t feel heard and listened to by medical staff. This was partly due to disrespect which is discussed further in 4.2.2 but also the ways in which medical staff sometimes struggled to understand or didn’t attempt to understand Aboriginal patients when they were communicating in ways that might have been different to what they are accustomed to.

*“Medical staff need to learn to listen to what’s being said. A common thing is “I can’t get any wind in my tubes”, or “I’ve got a runny belly” even though that’s a different way to explain it, the words tell you what’s wrong”.*

Aboriginal Peoples’ ways of communicating may be unique and culturally defined. Hence clinicians need to be aware of different ways of communicating illness and ensuring that patients feel they have been heard and listened to. Health literacy is intrinsically linked to cultural competence and understanding who is in the room at the time. As was mentioned above, Aboriginal Health Workers are often better able to mitigate the communication issues, reducing anxiety and increasing clarity.

Gender roles and expectations in Aboriginal cultures are important to consider in the context of health given the value that is placed on them by the individual. Ignoring these roles, for example by discussing women’s business with a male doctor, can bring about great shame and embarrassment, neither of which are conducive to a respectful and trustworthy therapeutic relationship.

### 4.1.4 Care and compassion

A common narrative expressed by interviewees was the importance of care and compassion. Some talked about how clinicians "just treated me like a number" and didn't want to build a relationship with them.

*"I have to fight for myself. Make them listen. Make them look at other symptoms… I'm not leaving until you do something."*

On the other hand, others talked about how compassionate and caring clinicians took the time to build a level of trust and understand their health holistically.

People often commented that they didn't want to return to GPs who rushed them and made them feel like a number they were trying to get through. On the other hand, several individuals discussed that they highly regarded clinicians who took the time to get to know them and wanted to understand their health holistically. They felt that, with these clinicians, they were more likely to share information and listen to their advice.

*"Other doctors just write a script and send you off; good ones take the time to know and understand you"*

Where care and compassion were lacking, people felt uninformed about the care process and were uncertain about what the next steps were and where to go. Some interviewees felt that at the end of certain stages of care particularly specialist care, the care journey was not explained to them in enough detail. Common questions people had include "why am I being sent to another doctor?", "what happens next?", "where am I in my care journey?".

On the other hand, some interviewees had entirely positive experiences within the service and when leaving on-going care. When leaving the service, they did not feel uninformed or confused at this point in their journey and were aware of their next point of care and what they could expect.

*"I appreciated doctors who showed compassion and explained what was happening and what would be happening next, it wasn't an in and out experience"*

*"I've never had any bad experiences with accessing services or with the health professionals that I see. Everything goes smoothly for me. I've found that Dr [redacted] is really good, and if there is something, he doesn't know he'll send me to someone else that does know."*

## 4.2 Cultural Marginalisation

Cultural marginalisation is a concept which underpins much of the poor service that Aboriginal People experience in the health system. This includes; disrespect, lack of cultural awareness, racism and stereotyping, and the ongoing impact of historical traumas. Overall, the challenge that many Aboriginal Peoples face when accessing the health system is services that are not responsive to their needs made worse when combined with racism and stereotyping.

It is important to recognise that poor-quality care in this section refers to the fact that while the 'technical' aspects of care may have been appropriate, may have been 'high quality', the care did not meet the needs of the Aboriginal person being cared for. So, to provide an example, while the right medication may have been given and the correct information provided, the nature of the interaction may have contributed to a lack of understanding by the patient, an inability to take the medication properly, a failure to take the medication, an unwillingness to go back for the follow-up appointment, all leading to poor health outcomes. So, despite the appropriate clinical decision being made it is, in this context, an example of poor-quality care.

### 4.2.1 Racism and stereotyping

Several interviewees talked about how their Aboriginality strongly influenced their initial engagement with the health system. Some felt as though their Aboriginal identity was being questioned by health workers. They felt disrespected when questioned whether they were Aboriginal because they may not have stereotypical Aboriginal features.

*"I felt like just because I wasn't Black, the doctor didn't believe that I was Aboriginal"*

Others felt that while they might have been acknowledged as Aboriginal, the clinician judged them and made false assumptions about them because of their Aboriginality. For example, one individual, a non-drinker and non-smoker, who was experiencing kidney-related health issues, was told it was because of their drinking and smoking.

*"They (clinicians) think if you drink or smoke you have kidney problems…I have never smoked or drunk before"*

This is not a novel concept. Previous research in this area has found that when presenting to a medical appointment or hospital, Aboriginal People are often subjected to judgemental, and racist assumptions based on their appearance (Abbott, Dave, Gordon, & Reath, 2014).

It is important to note that these experiences of stereotyping and racism are not necessarily a reflection of racist health professionals. While some of them may be, it also speaks to a greater issue surrounding the lack of cultural understanding in the health sector. For well educated professionals to not understand the complexity of Aboriginal cultures, even on a basic level is inadequate. Aboriginal culture is much more than the colour of your skin. It is about being connected, to land, to ancestors, to spirit. To belong to a community, to family (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014).

### 4.2.2 Disrespect

Disrespect, and the experiences described in this section, is something that is felt by the person. It impacts on relationships and whether intentional or done subconsciously, being disrespectful can negatively impact on the health of the individual and the community.

Several interviewees discussed that negative experiences with clinicians and other health professionals often meant they would not return. For some people, this meant they sought care from another clinician or provider. For others this meant they would simply avoid accessing that care. One interviewee talked about how she asked the doctor for the medication that was in her care plan and the way he responded made her feel like she was not important.

*"What, are you ordering your own medications now?"*

She said the doctor directed questions to her daughter because "when you get old you get a bit demented". As a result of this experience she chose to see another doctor. Another interviewee talked about how she could not afford an appointment with an orthopaedic surgeon immediately so went after some time. She felt the doctor made her feel disrespected by the way he questioned why she had not come in earlier. She felt he was not understanding of her financial circumstances creating an access barrier and as a result chose to not access that care.

Another interviewee spoke of an experience with a new cardiologist who told her she didn't have the disease she had long been diagnosed with, she was just fat. The cardiologist then proceeded to tell the woman's 24 year old granddaughter and 2 year old great granddaughter that "you're going to end up like her" and "you better put her on a diet". The person never went back.

*"I think it's time we got up and left because you've just lost a patient"*

Thankfully in this instance, the interviewee found a new cardiologist and is still receiving treatment, in a "culturally respectful" way.

### 4.2.3 Lack of cultural awareness

The workshop participants felt there was a lack of understanding of culture by some health professionals delivering the service or information. As previously stated, Aboriginal perspectives see health as more than just a disease. It is part of a holistic sense of wellbeing. In practice, this means health professionals need to be aware of the way health information is relayed back to the person.

For example, one participant recalled a situation where she was working with a lady with a range of chronic health problems. A non-Indigenous health professional had warned the woman that "her blood pressure would kill her one day". Culturally, for this woman, speaking of death like this could actually lead to her death, and cause real spiritual harm that directly related to physical harm. That speaking of it, "sung in" death itself.

*"The white fella sung me, they said I'm going to die, and die soon because my blood pressure too high"*

Careful explanation about the health condition, providing accurate health and treatment information, while respecting her cultural perspective (and spiritual experience) of the threat of death needed to be understood to support her effectively.

As stated earlier, a basic understanding of culture will help inform culturally appropriate communication. Understanding the holistic sense of wellbeing, encompassing the mind, body and spirit, is not fully recognised in our health system, which tends to focus on the clinical, physical aspects of health. This means that the impact of a miscommunication, between a "mainstream" health provider and Indigenous patient, can be extremely detrimental.

Similarly, the current health system does not recognise or acknowledge the expectations and family roles that Aboriginal Peoples take on, which can often inhibit them from accessing health services. For example, many of the women at the workshop discussed that they saw themselves as the homemakers, as well as the emotional and mental support system for their families. The impact of becoming sick seemed to be far reaching, and in some ways unexpected as compared to other members of the family. This reinforced cultural perspectives surrounding the roles of women in families and communities and the importance of the matriarchal system.

*"Women aren't meant to be sick"*

This means that going to hospital, which could result in being admitted for a long period of time, is not an option. Instead, these women spoke of forgoing the health care because otherwise the "house dies".

This experience is tied to cultural values and beliefs and the system needs to be cognisant of the impact it has on Aboriginal Peoples' access to healthcare. For many Aboriginal People, their connection to their family, kinship and community brings with it a sense of belonging and not performing those roles, for whatever reason, leads to feelings of shame and guilt. Their ties to those around them are of great importance and will continue to remain a high priority. Without a concerted effort to change the way the system helps them maintain their cultural connections while supporting them throughout their health journey, the health inequities will remain.

Another interviewee believed that the effort health services go to is just superficial and that to actually achieve cultural awareness and competence, there needs to be Aboriginal input embedded deep within the system.

*"When I visit [redacted] Hospital, I feel that no-one cares about my identity, no-one asks if you're Aboriginal or if you identify as such. The nursing care is fine. They are not culturally aware and have no reconciliation committee. I feel that they'll put an Aboriginal garden in or a yarning circle but won't have an Aboriginal advisory group."*

### 4.2.4 Intergenerational and past traumas

One of the women at the workshop spoke of the lingering fears she had about going to a hospital. She described a time when she had a serious leg wound but did not want to go to hospital in her home town. She noted that the hospital was the one that people went into and never come out. When questioned further, she explained that during the time of the Stolen Generations, many mothers would go to hospital to give birth and their babies would be removed from their care once born.

One interviewee noted that being away from her Country, her home, was hard. She would like to go back home and thinks her health would benefit from that, but says there's nothing to go back to, and all the services are in Sydney.

While experiences related to intergenerational traumas vary amongst Aboriginal People, it is important to acknowledge and recognise how both colonisation and the enforced policies built on racist platforms continue to affect health and wellbeing outcomes. Dispossession, displacement, forcible removals are collective experiences of a diverse culture, and the process to reclamation is critical for survival. (Holland, Dudgeon, & Millroy, 2013)

*"Involving all community representatives, particularly the traditional owners and respected leaders is key to the inclusion of local people to develop local solutions to improve health outcomes."*

The political and historical climate that preceded and continues today has left in its wake a huge sense of distrust amongst some Aboriginal People, yet trust is a fundamental feature of providing effective health care. Therefore, for health care to be appropriately provided to Aboriginal People, this history needs to be acknowledged.

*"We didn't know when we were young, about Aboriginality… I was Stolen Generation, that tears me apart. I am going through the Royal Commission now. So even that is hard… But you just have to get on with it. I'm 63 but it still affects me."*

## 4.3 Self determination

Self-determination refers to the ability of an Aboriginal person to both manage their own health and how their condition impacts their lifestyle. Both of these are examined within the context of the wider system and how it can restrict and constrain Aboriginal People's abilities to manage their own care and their other responsibilities such as family.

### 4.3.1 Being informed

A common narrative within the interviews was how receiving a diagnosis of a serious health condition often came as a shock. They felt that through living their lives, their health had deteriorated to a point they did not expect. While some individuals acknowledged their lifestyle choices may not have been the best, they didn't feel their health was bad enough to raise serious health issues. This is connected to one's ability to access healthcare and the right information. Some interviewees outlined that they were unsure how to distinguish serious health issues from minor issues.

One interviewee discussed that he first experienced his chronic condition when he was working. He felt discomfort in his chest but continued working believing it was minor. He collapsed and was noticed by a colleague and taken to hospital. He discussed that he was disappointed that this had happened because he felt he had not managed his health better. He felt that in his youth he was fit and physically in good shape and for a variety of reasons this changed in his adulthood.

*"I felt annoyed and disappointed that I had done this to my own health"*

While being shocked by a sudden health event was an experience expressed by many of those we interviewed, it raises questions about the accessibility of the health system and the lack of information provided to individuals who do. Routine contact with the health system could enable warning signs to be identified earlier. Moreover, more information would support Aboriginal People in knowing what to be aware of and how to identify and respond to anything of concern.

### 4.3.2 Self-management

A common theme for interviewees was the idea of moving from on-going care within the health system to greater self-management. Some Interviewees discussed that when they left the health service, they still had contact with a key clinician such as a GP or a specialist.

Others discussed that their health had gotten to a point where they were able to manage their health on their own. These individuals often talked about how, with the support and knowledge from a respectful health professional, they were now striving towards living healthier lifestyles, for themselves to help manage their own health condition.

*"I feel in control of my health, I go to the gym and eat better…helps when there is someone pushing you and motivating you"*

One interviewee talked about his journey of obesity, initially being cared for largely by the health sector to now, self-managing his condition. He talked of managing his own health with guidance from his GP and how he feels well supported and in control of his health. He said that while he is managing his health, he would not be able to do it without the support he has had. He feels that support is a big factor in self-management, with a lot of people giving up without it. He talked about the value of having someone who was checking up on him and encouraging him.

A key part of self-management was utilisation of traditional Aboriginal healing as opposed to mainstream care. Some interviewees talked about the importance of the connection to Country and their ancestors. Connection to culture and traditional healing practices has shown to improve personal strength (Calma, Dudgeon, & Bray, 2017). Encouraging Aboriginal People to, where appropriate, finds way of maintaining their health in a culturally sound way is empowering for them and aligns with the right to self-determination and self-governance as set out in the Ways Forward report (Swan & Raphael, 1995)

*“They also wanted me to go back for exercise, but I’d rather walk close to home than be on a treadmill. I walk and I connect to country and speak to the mother (creator) that’s what I prefer.”*

### 4.3.3 Impacts on life

Several interviewees discussed how their chronic condition meant many changes in their lifestyle. For instance, interviewees talked about how their chronic condition and subsequent treatment meant they were not able to work, play sport, socialise as much, eat and drink the same things and impacted on their family responsibilities.

*“Because I couldn’t move I gained a lot of weight, I couldn’t work or play sports”*

One individual spoke about how he was no longer able to work after his diagnosis and also unable to easily leave his home. He talked about how, despite his chronic condition having a severe impact on his ability to socialise, he was supported well by his friends. He mentioned that his friends were a strong support system and they were always there for him when he was unable to leave his home.

Several interviewees discussed the impacts that their health had on their family responsibilities. A common narrative was feeling that their health condition would impact negatively on their ability to look after their family and maintain their responsibilities.

*“I have always been aware that I need to live for my daughter”.*

In line with this narrative was discussion about not wanting to be seen as a burden on family. Interviewees recognised that they had family as a strong support network but often prioritised the interests of their family to the detriment of their own health.

As has been discussed, connection to community, Country, family and kin plays a huge role in the health and wellbeing of an individual. However, that connection and belonging comes with it expectations of roles and duties to be performed. The impact of the health system and health outcomes on these roles can cause feelings of shame and guilt to be felt by the individual. While this is not always something the system can rectify, it is important that there is an awareness of it to facilitate support and ensure these changes don't negatively impact on the person's life further.

# 5. IMPLICATIONS FOR SERVICE IMPROVEMENT

## 5.1 Context

- For some Aboriginal people there is the experience of life-long trauma that can affect how they interact with the health system. This may manifest itself in anger, shame, lack of confidence, a sense of 'not being understood'. To tackle an issue first requires an acknowledgement that it exists. Work needs to be done so that this context is better understood by health providers.

- Health services we do have may not be culturally sensitive and may not understand the best ways to effectively engage with Aboriginal patients and the best ways to "heal" for Aboriginal people. There were a number of patients who were interviewed who were affected by the stolen generation and the generational trauma that followed.

- Related to the above, there is a trend, evident in the interviews, that if an interaction with the health service was not successful there is a tendency not to try again. It can take a lot of effort for an Aboriginal person to find a doctor that they feel comfortable with so when it does not go well it is often hard to try again.

- The health of Aboriginal people is highly impacted by the social, cultural and political context, which cannot be ignored if improvements are to be made. Thus, the NBMPHN and NBMLHD will need to work with other agencies to tackle the wider socioeconomic and psychosocial needs facing Aboriginal People in the Nepean Blue Mountains region.

## 5.2 Improvement ideas developed in response to the findings by the NBMPHN and NBMLHD

Following the delivery of the final report, the Nepean Blue Mountains Primary Health Network, the Aboriginal team of the Local Health District, and Aboriginal project partners identified potential opportunities in response to the project outcomes. Some of these improvement recommendations included:

- Development of a map of Aboriginal and Torres Strait Islander-specific and Aboriginal and Torres Strait Islander-targeted services across the service region, noting gaps and expressed community needs, to include in NBMPHN and NBMLHD planning and commissioning initiatives. This is in response to participant feedback relating to the need and preference for culturally aligned services.

- Establish regional protocols to express community-identified criteria for best practice in Aboriginal and Torres Strait Islander health service provision. Following the development of protocols, it is suggested that the development of self-assessment materials for service providers be developed to assist providers in their own improvement activities in line with community-expressed needs.

- Conduct a review of existing health literacy products targeting Aboriginal and Torres Strait Islander peoples. Consider the adaptation and/or development of regionally-targeted resources to improve community health literacy and aide in individual decision making relating to health promotion, illness prevention and treatment planning.

- Develop a regional vision statement/plan for the funding or commissioning of new services for Aboriginal and Torres Strait Islander community, incorporating community-identified needs, service features, and priorities. Establish an in-principle agreement between the PHN, LHD and ACCHO for the consideration of this vision in all new funding initiatives.

- Review existing strategies in place to assist GPs in effective identification of Aboriginal and Torres Strait Islander patients in collaboration with the Integrated Team Care Team. Consider development of targeted regional resources exploring the diversity of Aboriginal and Torres Strait Islander identity.

- Seek and enable access to deidentified regional examples of best practice in Aboriginal and Torres Strait Islander health care. Develop examples into a story-based format, and explore opportunities for the sharing of these examples either through training, newsletters and/or online platforms.

- Work with local communities, in each region, to identify the types of cultural supports or opportunities that could be facilitated. Seek to facilitate, fund/commission and/or invite providers of culturally-based health and wellbeing programs accordingly, for example Traditional Healers or preventative health initiatives.

- Explore opportunities for a regional seminar/workshop/conference with service providers to identify and build effective local approaches, share ideas, and build networks for high quality health care for Aboriginal and Torres Strait Islander communities.

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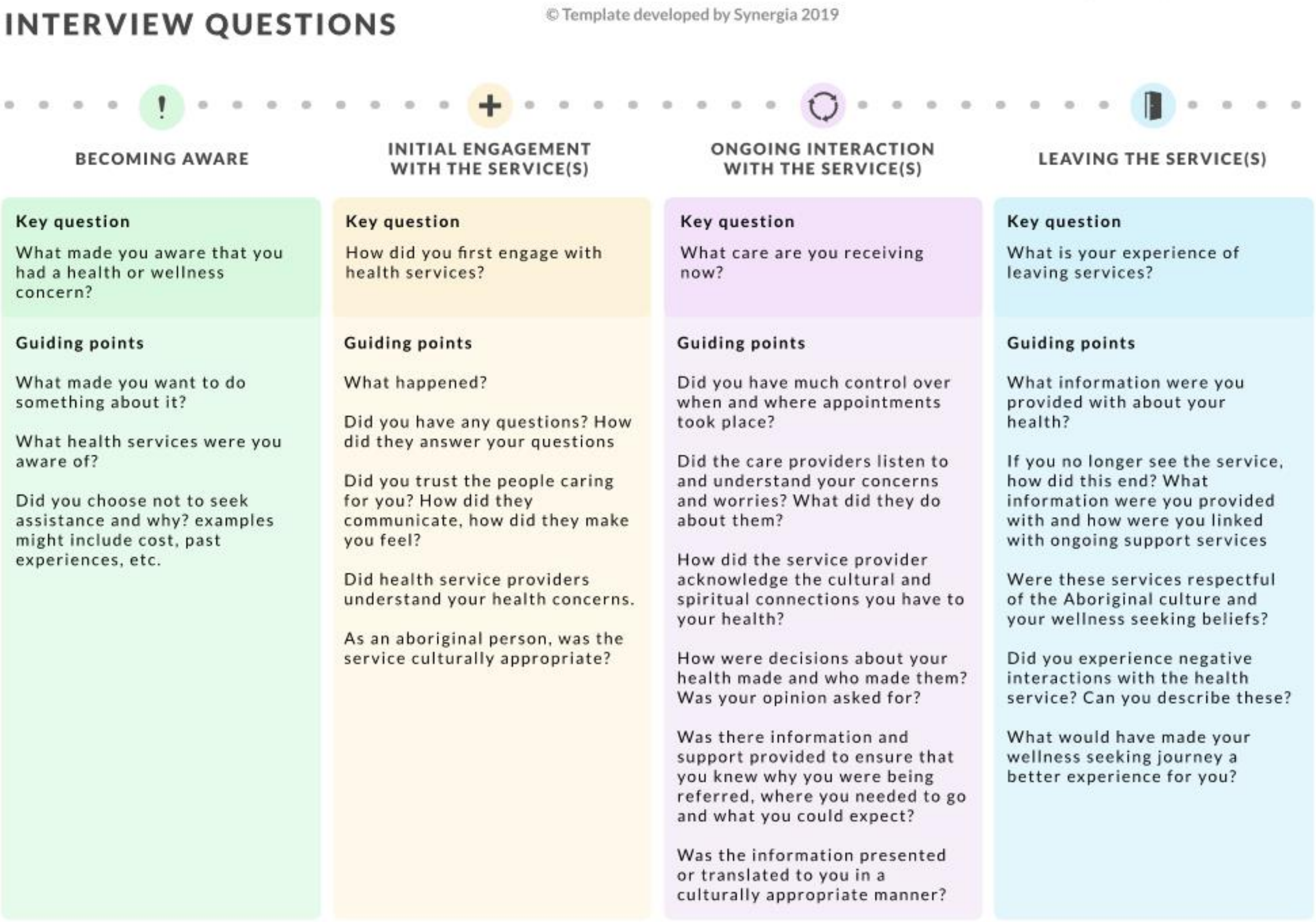
# 7. APPENDIX 1



## INTERVIEW QUESTIONS

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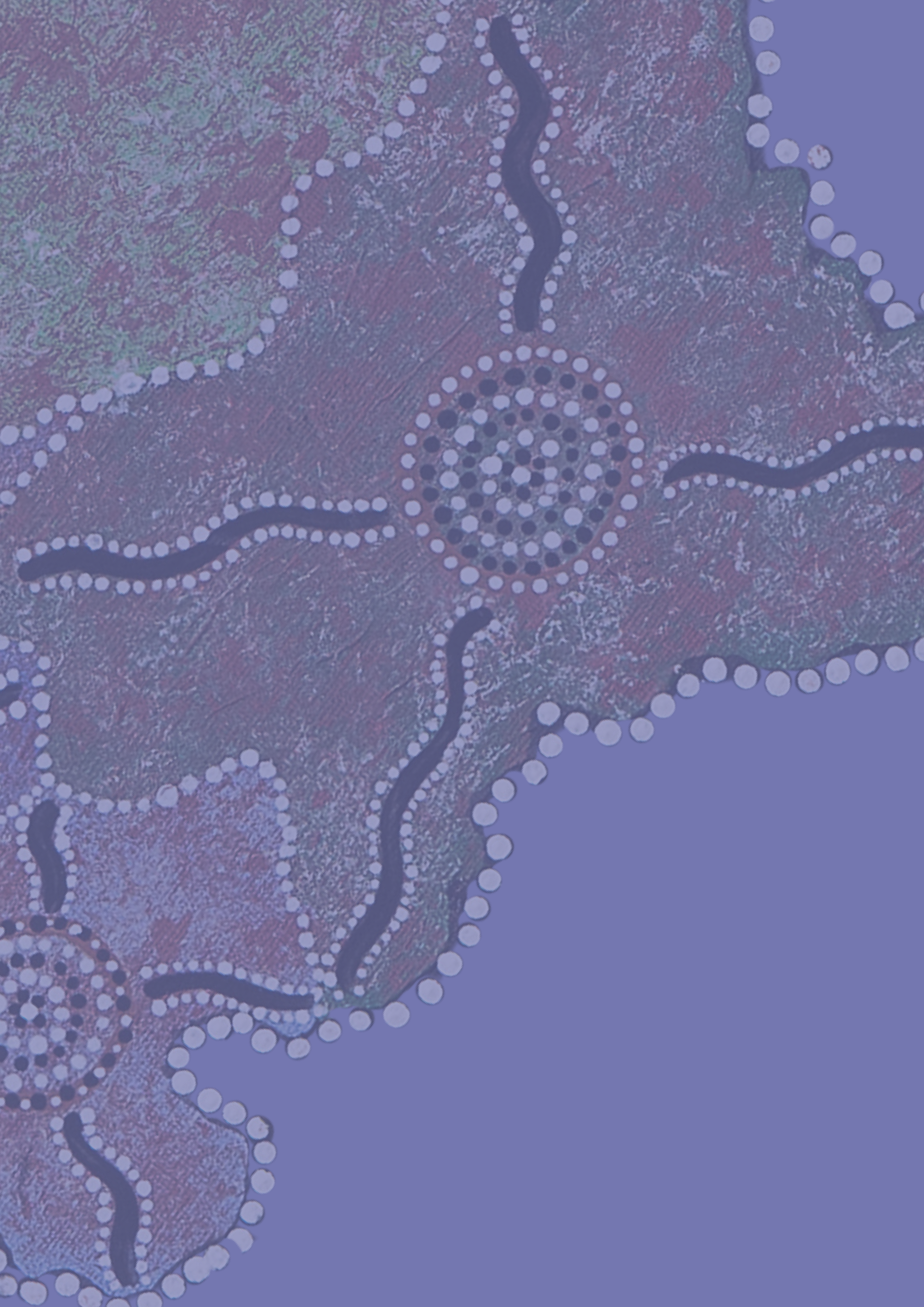
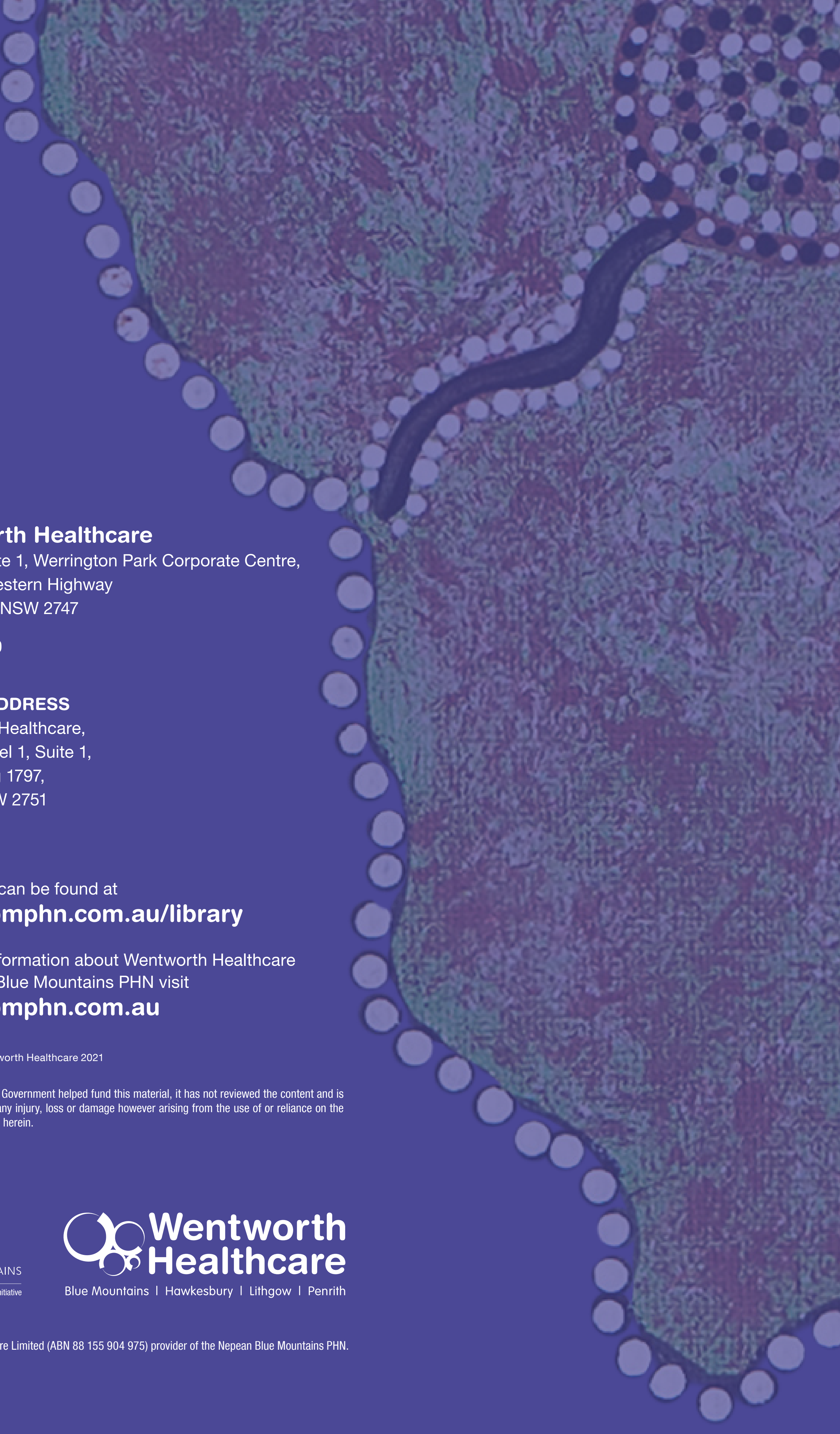
| BECOMING AWARE | INITIAL ENGAGEMENT WITH THE SERVICE(S) | ONGOING INTERACTION WITH THE SERVICE(S) | LEAVING THE SERVICE(S) |
|---|---|---|---|
| **Key question**<br>What made you aware that you had a health or wellness concern? | **Key question**<br>How did you first engage with health services? | **Key question**<br>What care are you receiving now? | **Key question**<br>What is your experience of leaving services? |
| **Guiding points**<br>What made you want to do something about it?<br>What health services were you aware of?<br>Did you choose not to seek assistance and why? examples might include cost, past experiences, etc. | **Guiding points**<br>What happened?<br>Did you have any questions? How did they answer your questions<br>Did you trust the people caring for you? How did they communicate, how did they make you feel?<br>Did health service providers understand your health concerns.<br>As an aboriginal person, was the service culturally appropriate? | **Guiding points**<br>Did you have much control over when and where appointments took place?<br>Did the care providers listen to and understand your concerns and worries? What did they do about them?<br>How did the service provider acknowledge the cultural and spiritual connections you have to your health?<br>How were decisions about your health made and who made them? Was your opinion asked for?<br>Was there information and support provided to ensure that you knew why you were being referred, where you needed to go and what you could expect?<br>Was the information presented or translated to you in a culturally appropriate manner? | **Guiding points**<br>What information were you provided with about your health?<br>If you no longer see the service, how did this end? What information were you provided with and how were you linked with ongoing support services<br>Were these services respectful of the Aboriginal culture and your wellness seeking beliefs?<br>Did you experience negative interactions with the health service? Can you describe these?<br>What would have made your wellness seeking journey a better experience for you? |





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