“It's more than pieces of paper”:

Understanding Aboriginal and Torres Strait Islander lived experiences of kidney health

Louise Graham

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Faculty of Medicine and Health

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CULTURAL CARE WARNING NOTICE

Abstract

This thesis explores the lived experiences of a group of Aboriginal and Torres Strait Islander people with kidney health challenges. It explores their interaction with health information, clinical education and health advice. This research gives a voice to their experiences in nephrology and describes the interactions they had with their health and well-being care providers.

As qualitative researcher, this work seeks to understand their insights and perceptions of health literature; it positions the participants' perspective as central to the research. It highlights the positioning of chronic kidney disease (CKD) as a health priority for the participants and gathers data about their experiences as they sought care from their health professionals. Hearing the different challenges and barriers that the Aboriginal and Torres Strait Islander participants faced, and their attempts to best manage their CKD, assists in developing an understanding of the adversity that they must face and overcome.

This research highlights the importance of understanding one's own health and demonstrates the importance of using relevant and patient centred health information and education. I have used Indigenous methodology and a decolonisation approach that is ethically appropriate, ensuring the establishment of meaningful relationships throughout my research and facilitating the participant experience through engaging about the health, information, education and advice they received.

The overarching purpose of my research was to gain an insight into the lived experiences of CKD and patient health information. In hearing the participant's voices and gaining an understanding of their lived experiences within nephrology, it became evident that there is much to be done to improve much of the CKD patient's experiences. The participant's data points to solid recommendations for change in how CKD health information and services are offered within an Aboriginal and Torres Strait Islander context.

Statement of originality

This is to certify that the content of this thesis is my own work. This thesis has not been submitted for any other degree or purpose or passed through artificial intelligence. No content produced by generative AI tools has been used in the preparation of this thesis.

I certify that the intellectual content of this thesis is the product of my own work, and that all assistance received in preparing this thesis and all sources have been acknowledged.

Louise Graham

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Acknowledgements

I would like to thank my two supervisors Michelle Dickson and Martin Howell for encouraging me to undertake this research on renal failure and kidney health in Aboriginal and Torres Strait Islander people and communities. I would like to acknowledge that I needed the experience and support of Michelle and Martin to complete my Masters, as they encouraged me to develop my research skills to enable me to interview patients who identified as having renal failure. I had a strong desire to explore and understand their first-hand experiences by exploring their knowledge, awareness, information, education, and perspectives on renal failure and kidney health. I would also like to thank Nicole Scholes-Robertson for her support and networking in helping me to access participants. I also wish to thank the participants and clinicians who took part in this research. Together I hope this research can contribute to a better understanding of lived experiences of kidney health and treatment and inform important changes. Finally, I would like to thank the person who originally inspired my research, my mother, Mary, who died of renal failure. I would like to my new family of adopted possums, in honour of Mary; Denise, Gabrielle and Charlie have shared the company of this research.

This image is of Mary-Botanica, a ring tail possum who has been with me for my Master of Philosophy research journey (Image taken on 13th July 2022 photographed by Louise Graham).

Author’s notes

I am an Arrernte woman, (Arunta lands, Santa Teresa also known as Lynette Apurte) and my research focuses on patient information, health literature, education, knowledge and understanding of the progression of renal failure and kidney care.

My research was inspired by my mother Mary, who died of renal failure. Throughout her health journey she continued to ask to be fully informed; she asked for health information at each stage, and often became frustrated at the multiple sources of information that often were conflicting. She continued to ask questions and seek information, believing that her death was hastened for no reason, given the mixed renal health information and advice she received about her kidney health. This research was also inspired by a conversation she had with a health professionals when she was not appropriately cared for; nor was her needs being listened to, or her questions being answered. As an Aboriginal woman, she saw and experienced in the inequities, inequalities, discrepancies, and inadequacies in renal care, but most importantly she asked to be fully informed but was not. When I was given the opportunity to do my Master of Philosophy (Research), there were so many areas I could explore with research areas related to renal health and renal care. However, as a main carer I was interested in the lived and shared experiences throughout the renal health care journey, from diagnosis to approaching death. Above all I noticed I was most interested in the fact that patients, like Mary, were often not completely aware of the full extent of their own renal health status and therefore were unable to make informed choices and decisions, and plans. I drew my thoughts back to Mary’s experience of being put on dialysis, being told by a health professional that “‘dialysis is to hook you up to stabilize you for a transplant, not to hook you up to die”. However, Mary described dialysis as “It’s torture”, and as an observer, carer, and family member it was like watching torture.

I became aware of the number of patients around Mary who were starting dialysis without being fully informed about the process and its impact it had on body, mind, and spirit. Many of the patients spoke openly to Mary and to me about not wanting to be reliant on dialysis and talked about wanting to come off dialysis. As a primary career and family member, these kinds of experiences were confronting, especially because I was very aware that Mary, and many other dialysis patients on dialysis, had not had the opportunity to discuss how dialysis would affect them and those around them. I heard many experiences of not receiving accurate, supportive information, of not having shared decision making, and of not having questions answered appropriately. It was those experiences that made me think about renal health and renal treatment health information and communication.

I lived through Mary's ongoing determination to asking to be fully informed and not providing her with information when she requested it, only to see her receive conflicting advice and rapid-fire, "stock standard" responses that only partially answered her questions. I also observed others also being given a range of information and resources that did not seem to help or assist them develop a fuller understanding of their health status, condition or treatment options available. I also saw that Mary and her peers often needed diverse information, all needed different information at different times, but a "one size fits all" approach was given to them all, and one size did not fit all- it did not work. As a carer survivor, I want to use my research to explore the lived experiences of some Aboriginal and Torres Strait Islander people with health information in relation to their renal health journey. Importantly, I feel privileged to be able to share these experiences. Importantly, I feel privileged to be able to share these patient voices and better understand how they are using their health information to improve their health outcomes and treatment choices.

Contents

Abbreviations

ACCHS	Aboriginal Community Controlled Health Services
ACHS	Aboriginal Community Health Services
AHMRC	Aboriginal Health and Medical Research Council
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Services
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
ANSN	Australian and New Zealand Society of Nephrology
AV Fistular	Arteriovenous fistular
AV Graft	Arteriovenous graft
BP	Blood Pressure
CKD	Chronic Kidney Disease
CTG	Close the Gap policy
CVD	Cardiovascular disease
CVC	Central venous catheter
DoH	Commonwealth Department of Health
eGFR	Estimated glomerular filtration rate
ESKD	End-stage kidney disease
HD	Haemodialysis
HTN	Hypertension
KHA	Kidney Health Australia
MBS	Medicare Benefits Schedule
NRHA	National Rural Health Alliance
PD	Peritoneal dialysis

PD Catheter	Peritoneal dialysis catheter
RRT	Renal replacement therapy
RACGP	The Royal Australian Collage of General Practitioners
WHO	World Health Organization

Chapter One: Overview

The rationale for this research

I have come to this research with the lived experience of caring for a parent, as she moved through her renal health journey from diagnosis through to end of life. I acknowledge that this has motivated me to undertake this research, and I see that motivation as a strength. The inspiration of my research came from my mother who passed away from renal failure. I walked with my mother through her journey, and noticing many of her healthcare professionals tried not to keep her fully informed; and her questions were mostly met with silence. As a carer, I wanted to do more. Now, as a researcher, I wanted to find out:

- What health information and resources patients received, and whether this helped the patients make lifestyle changes or modifications to improve their own health, and to be aware of making decision and about their kidney treatment plans.
- Where patients sourced their information from, and whether they found it useful or beneficial.
- What patients understood about their own health treatment options and care plans, and whether the information they received helped them make informed decisions.

This research includes Aboriginal and Torres Strait Islander ways of engaging with health services, health literacy, information and advice. I know from personal experience, that health information for a patient is also important to family members and carers.

This research is important because it seeks to understand what information and education is beneficial and useful to for patients and therefore provides information that can contribute to better health outcomes and thereby improve quality of life, through gaining a better understanding of kidney disease and options available.

My research aims to improve health outcomes for Aboriginal and Torres Strait Islander patients' health outcomes by developing a better understanding of the information and education patients are receiving, exploring what has worked well and what information could improve their health and maintain their health outcomes, and influencing the way information is developed and shared by health professionals.

Developing my research question

My research focuses on improving health outcomes for Aboriginal and Torres Strait Islander people with renal failure and understanding their perspectives on their lived and shared experiences of renal failure or decline in their renal function. I have a particular focus on the health information and advice that patients have received throughout their renal health journey.

I hypothesise that their renal health journey could be improved if Aboriginal and Torres Strait Islander renal health patients experienced a tailored approach to renal health resources and information, rather than a one-size-fits-all approach. To explore this, I decided to develop an understanding of the lived experiences of several Aboriginal and Torres Strait Islander people with kidney disease. My research question is based on:

What is the lived experience and value of renal health literature, information and resources in the lives of a group of Aboriginal and Torres Strait Islander people with kidney disease (renal patients)?

This research was inspired by personal observation where patients wanted to be fully informed, and as a carer I observed many health professionals and their approach to the patient. It was interesting that my mother was a registered nurse, she taught me many things including having humanity and treating people equally; some of these life lessons seemed to have been lost in the health professions caring for my mother. My mother wanted me to be with her throughout her renal health journey, because of the disrespect and treatment that she was receiving. Her support was very limited, and she ended up with a “wait and see approach”; her treatment team did very little to provide information and education to help her understand their decision making. And she was rarely involved in making any decisions at all. She was sent on to “end of life care” which meant that she was left to rot to death, with some conditions that caused her extreme pain and distress but were largely neglected.

I observed her health professionals and on reflection, many decisions about her care were made on financial grounds, only offering lowest cost options even if she might afford an alternative. I saw patients who wanted to be fully informed and who, like her, never had never been fully informed. So, I wanted to know if other patients had been able to improve their own health conditions and choices of care through information and health education provided to them. I wanted to explore whether information and involvement in decision making would enable patients to become empowered and able to self-manage, self-care and to have a better quality of life.

I planned for this research to explore whether the information patients received was useful and whether they understood the resources. Importantly I wanted to understand if the information given to patients enabled self-care and self-efficacy, in a culturally supported environment (T. Power et al., 2021). This research aims to integrate the shared and lived experience with the participants’ personal journeys, stories, and perspectives, giving a voice to their journey with CKD.

Thesis argument

Throughout my research and dissertation in my thesis, my argument is to consider the ways in which information is given or is not given freely, and the value of that information to . I argue that increased access to culturally supportive information and services can lead to improvements in quality of life and health. In addition, I argue that improved communication with health professionals, and increased access to quality information can support patients to better understand their CKD journey and treatment options, enabling greater engagement in decision making and supporting for Aboriginal and Torres Strait Islander people to live longer with their condition.

My research will argue that kidney patients need more specific, personalised, and individualised information, that is culturally appropriate and respectful, rather than information disseminated on a generic basis, that is not specific to the patient's needs(Fraser et al., 2013).

Thesis structure

Chapter one

In Chapter one I present my study rationale. This is a qualitative, research study examines the types of information designed to improve a person's health status. My research and the participants lived and shared their experiences of renal failure. My own lived experience as a carer inspired me to explore, we can improve the information and quality of health knowledge, information and resources available to improve the patients' quality of life and health. I also believe that information, literacy, and education is not freely available or disseminated and can be confusing and even overwhelming because it is continually changes and is not always specific or individualised to the patient needs.

Firstly, it should be noted that chronic kidney disease (CKD) within the field of nephrology, can become complex for various reasons, due to health complications and underlying medical conditions and if health problems are not controlled can become serious and even life threatening. Chapter one presents my thinking about the fundamental issue of being fully and properly informed, so the patient receives adequate, sufficient and appropriate information to be able to make appropriate decisions and plans (Hoy et al., 2010).

I propose that, in many situations, it appears that patients are not, or feel that they are not, always properly informed. My hypothesis is that information is not always accessible, freely distributed and may be restricted, including questions asked of patients. In the first chapter I present my proposal, considering that is part of our human rights to be informed and to have access to medical treatment and care, but it my observations suggest information seems to be denied or withheld, withheld or not freely given out. My observations (based on personal experiences) are that patients are not informed, which creates gaps that then become labels on to the patients' medical records creating more tension, disengagement or distress and even limiting treatment options, or medical treatments that are changed or not being made available to them. I wanted my research to explore this and to make a difference to the health of Aboriginal and Torres Strait Islander people, families and communities by developing a better understanding of what information is being shared with patient and developing an understanding about what is helpful and useful (from the patient perspective).

Chapter two

In Chapter two, I describe the Aboriginal and Torres Strait Islander context of renal health. I present the historical policy and practice developments that have impacted on Aboriginal and Torres Strait Islander people and their health, within the context of CKD.

Chapter three

In chapter three I present facts showing Aboriginal and Torres Strait Islander people having increased rates of CKD, when compared with the wider population (Health & Welfare, 2023b). I also present literature on the challenges of accessing culturally appropriate care, especially for people who want to seek treatment on Country, but services may not be accessible to them. I present the paucity of patient-centred health research and literature, including patient-focused information and education for Aboriginal and Torres Strait Islander people, and their health care management and self-care to make meaningful changes and to improve their own CKD health status.

Chapter four

In chapter four, I present my methodology and methods based on lived and shared experiences and perspectives, reinforced by a theoretical framework that has guided my research. My research focused on the voices, experiences, perspectives and knowledge gained during their journey of living with kidney disease and how their perspectives, experiences, influences and impacts on their health and wellbeing.

Chapter five

In chapter five I present the findings of my research, derived from the analysis of the data, that I generated from the participant interviews, and present two main themes and sub-themes:

Theme 1: Challenges when trying to access health education

Subthemes:

1.1 Withholding information regarding treatment options

1.2 Limited resources provided

1.3 Missed opportunities to delay disease progression

1.4 Power imbalances limiting sharing of information

1.5 Psychological impact following attendance.

Theme 2: Advocacy for self and others

Subthemes:

2.1 Seeking own resources to supplement knowledge

2.2 Yearning for culturally appropriate care

2.3 Developing relationships through informal yarning of shared experiences.

Chapter six

In Chapter six I present a discussion of the findings. Following Indigenous ways of yarning to share lived experiences and learning, I reflect both on the analysis of findings and on my own personal observations and experiences as a carer for my mother who died because of her CKD. Data analysis and personal reflection allow me scope to present a discussion on how patients are provided information and what information is useful from the patient perspective).

Chapter seven

In chapter seven I present the strengths and the importance of my research from an Aboriginal and Torres Strait Islander perspective, emphasising that giving voice to patients allows for better understanding of what works for them. I will the discuss some of the limitations of my research and propose further research for different areas of kidney health information, education, awareness and understanding of patient needs.

Chapter Two: The Aboriginal and Torres Strait Islander context

Aboriginal and Torres Strait Islander history and colonisation

In Australia, Aboriginal and Torres Strait Islander people are our First Nations people. We have lived on this land for over 40,000 and 65,000 years, as evidenced by archaeological sites (Langton, 2011). However, we have been documented our presences here for much longer. We, Aboriginal and Torres Strait Islander people, have a connection to the land, to the Country we come from. We are connected by our culture, our ceremonies, our practices, our language, our traditions, our beliefs and our art (Langton, 2011). We have our own identities and languages, with several hundred language groups existing across Australia, some with multiple dialects and each with their own cultural practices, language and humanity. We are connected to our Country, to our families and to our relationships, through kinship, and the extended families that make up our community. We are deeply connected to the environment, to natural resources connect that connect us to bush food practices and bush medicine, and to our own traditions before per-colonisation (Langton, 2019). This is important given the historical context of colonisation and its impact on our health and wellbeing. Importantly, we need to understand our own health issues in our own language and through exploring what works for us, in order to improve our health outcomes to live quality of health and quality of life (Muscat et al., 2018).

Before colonisation, Aboriginal and Torres Strait Islander people were generally healthy. However, colonisation had a devastating impact on our communities, introducing infectious diseases, viruses and infections into Aboriginal and Torres Strait Islander communities. This had an immediate impact on health and well-being. Many infectious diseases went untreated, such as tuberculosis, measles, smallpox, and syphilis, which resulted in devastating communities, rapidly increasing mortality and creating foundations for inequitable health conditions that continue to challenge Aboriginal and Torres Strait Islander communities and individuals (Carson et al., 2007).

Colonisation resulted in a highly racialised system, that excluded Aboriginal and Torres Strait Islander people from most parts of post-colonial life, implementing a systematic approach to class stereotyping from 1778 onwards (Langton, 2019). Colonisation imposed the notion of "*Terra Nullius*", establishing the belief that this land "belonged to no person" therefore belonged to no one. This was the foundation of British rule which produced government policies imposed on communities, each of which had a profound impact that devastated the health and well-being of Aboriginal and Torres Strait Islander people (Chalmers, 2020; Keenan, 2020). Since the start of colonisation government policies have displaced communities, engaged in missionary controls, and removed children from their families to assimilate into the white way of life. Such policies have contributed to devastating losses of connection to culture, cultural identity, kin, and to Country (Geissler, 2021a, 2021b; Hobbs, 2023). Government policies and practices continue today, in different forms. An example of assumed displacement is shared by Stevenson (2024) as he describes an experience where the federal police, who did not recognise him as a local, and pulled them over on a bush road on their Grandmother's Country. Desiring to live on Country Stevenson was asked "who are you and what are you doing here?" Stevenson believed those words should have been reverse, and asked the other way around, with Stevenson asking the police "who are you and what are you doing on my Country." Stevenson shared this contemporary example of racialised harassment on their own Country, stating "this is where I grew up…but they took my license details and still breathalyzed me."

Early government policies affecting Aboriginal and Torres Strait Islander populations and communities

Ongoing British rule imposed new laws introducing various ‘protection’ acts, laws and policies, which have had a devastating and profound impact on the health and well-being of Aboriginal and Torres Strait Islander people. One example is where Aboriginal and Torres Strait Islander children were removed from their families, known as assimilation between 1910 and 1970, which displaced many Aboriginal and Torres Strait Islanders children from their families and communities who have subsequently lost links to identity, connection to culture and to County (Thomson, 2024).

Colonialisation brought policies that had devastating effects on Aboriginal and Torres Strait Islander populations and communities. Even though each State or Territory had its own versions of acts of government acts and policies, they all have similarities that were aimed at not recognising the sovereign rights of Aboriginal and Torres Strait Islander people (Durey, 2010; Durey et al., 2012; Gatwiri et al., 2021). Many government acts and policies revoked the fundamental rights of Aboriginal and Torres Strait Islander Australians (Foster, 2023; Nicholas, 2020). The Assimilation Policy (1936-1950) that sought to integrate Aboriginal and Torres Strait Islander people into mainstream Australian society, allowing the government to control Aboriginal and Torres Strait Islander people and communities, which led to inequality, inequity, injustices and disparities between Aboriginal and Torres Strait Islander communities (Thomson, 2024). During this period there was an emphasis on child removals, with the vision that removing children from cultural influences would result in them assimilating into a non-Indigenous way of Australian life. This period was also often referred to as the Stolen Generation and also saw efforts to support segregation, discriminatory practices and systematic racism that enabled trauma to take hold and contributed to ongoing intergenerational trauma (Durey, 2010; Durey et al., 2012).

Later, the 1967 National referendum sought to amend the Australian Constitution to grant the right to vote, and other basic human rights, including the right to be counted in the census and to be an Australian citizen. While the referendum passed on the positive, the government continued to ignore some fundamental human rights and freedoms (Nagel et al., 2020a; Nygh & Butt, 1997). Importantly, more recent policies focused on self-determination, empowerment and respect for Aboriginal and Torres Strait Islander people as self-governing, and self-sufficient to develop and exercise our fundamental rights. However, as recent history shows, recognition of us as a sovereign people with rights and voice continues to be a challenge across the Australian population.

The current situation: recognition of Aboriginal and Torres Strait Islander people as Australia's 'First Peoples'

The Uluru Statement from the Heart inspired a call for the most recent Australian Referendum (2023), seeking the opportunity for Aboriginal and Torres Strait Islander Australians to be constitutionally recognized as the First Peoples of Australia in the Constitution. The negative outcome of the 2023 Referendum resulted broken hearts and much pain for Aboriginal and Torres Strait Islander people as the Australian population voted against recognition and voice of Aboriginal and Torres Strait Islander people (Morris & Freeman, 2023; Rubenstein, 2018).

The Uluru Statement of the Heart formed a political agenda and called for significant constitutional reform to provide hope and acceptance at the Commonwealth government level (Rice, 2024).The recent 2023 referendum, held on the 14th of October 2023, sought to explore the possibility of making changes to the Australian Constitutional Declaration. Under this proposed change, Aboriginal and Torres Strait Islander people would be recognised as ‘First Peoples of Australia’. This would be seen as an important progressive step towards enhancing human rights issues for Aboriginal and Torres Strait Islander people. However, the referendum did not eventuate, and ultimately resulted in a hurtful, negative outcome. A positive outcome could have potentially contributed to the enhancement of human rights issues for Aboriginal and Torres Strait Islander peoples that could have the capacity to change the life trajectories for many people (Anandakugan, 2020; Morris & Freeman, 2023; Rubenstein, 2018).

The negative result remains, and we are still not included in the Australian Constitution; our places at the policy making and decision-making tables remain empty (or filled by very few), and our voices silenced through lack of acknowledgement and inclusion. We continue to feel the absence of progress towards establishing a Treaty or any other forms of recognition for Aboriginal and Torres Strait Islander people, that would acknowledge and empower us (Morris & Freeman, 2023).

There are ongoing discussions about sovereignty and co-existence with the current system, with discussions about the recognition of Aboriginal and Torres Strait Islander people. The referendum sought to recognise culture and empowerment for Aboriginal and Torres Strait Islander people (SBS, 2024) but now the emphasis is on a ‘path forward’ approach, though it appears that no new ideas or new concepts working with Aboriginal and Torres Strait Islander people have been proposed in any major way. What remains is the need to acknowledge and empower Aboriginal and Torres Strait Islander people, who remain vulnerable under the current constitutional status. There is an opportunity to strengthen our rights and gain recognition for justice that has potential to have a continuing impact on health and wellbeing (Amnesty, 2024).

The opportunity presented to the health sector: privileging Aboriginal and Torres Strait Islander voice and culture

Aboriginal and Torres Strait Islander people are best placed to lead kidney health education, programs and information to improve health outcomes, and yet our voices are not often heard (Jones et al., 2020; Saxby et al., 2024; Taiaroa & Blow, 2023). Evidence suggests that health services that show cultural awareness, sensitivity and respect for Aboriginal and Torres Strait Islander people can contribute to positive health outcomes for their patients (AIoHa, 2023).

However, there are many challenges and barriers facing Aboriginal and Torres Strait Islander patients as they seek to access health care, including physical access and availability of local medical services, accessing culturally appropriate doctors, specialists in nephrology, and health professionals (AIoHa, 2023; Hughes et al., 2023; Kelly et al., 2022).There is also a growing recognition of the importance of having Aboriginal and Torres Strait Islander health professionals who can communicate and engaging with the patient to improve their own health outcomes (Gotlieb et al., 2022; Gwynn et al., 2015) .

Literature describes significant numbers of Aboriginal and Torres Strait Islander patients still not being provided with health literature, information and education about their treatment options that is culturally aligned and respectful of their needs (Ghamrawi et al., 2023; Gwynne et al., 2018; Ramsey et al., 2017; Rheault et al., 2019). These missed opportunities can lead to difficulties in planning and decision-making, often resulting in bare minimum medical treatment (Askew et al., 2021; D'Costa et al., 2025).

It appears that Aboriginal and Torres Strait Islander patients find themselves in a position where they are caught between two worlds, navigating the health system between non-Indigenous and Indigenous ways and practices. This situation can often result in health matters, where they go untreated and their concerns are overlooked, and as a result their health deteriorates quicker, or they have poor health outcomes (Askew et al., 2021; Bernardes et al., 2018; Pascoe et al., 2025; Rankin et al., 2022; Thackrah et al., 2022). Recent formalization of patient navigator roles in health services seeks to address some access and navigation challenges for Aboriginal and Torres Strait Islander patients (Mistry, 2024; Rankin et al., 2022; Scholes-Robertson et al., 2022).

How we support Aboriginal and Torres Strait Islander kidney health through policy

It is understood that improving the health of Aboriginal and Torres Strait Islander people's health is a matter of national importance and is a national priority, and chronic diseases are recognised as a significant concern. Moreover, Chronic Kidney Disease (CKD) is acknowledged and prioritized in national plans as a health issue (Australia, 2019; Health, 2021). However, there is still a gap across multiple determinants of health that affects the kidney health of Aboriginal and Torres Strait Islander people (Lakhan et al., 2022; Nagel et al., 2020b) . Close the Gap policy reform seeks to address multiple determinants of health that have potential to impact on kidney health (Baldwin et al., 2025; Recabarren, Dominello, et al., 2024).

Reflections on CTG progress suggested that integrating appropriate co-decision-making and increasing Indigenous participation in health has scope to improve health outcomes by empowering Aboriginal and Torres Strait Islander people with choices and rights, including human rights, intertwined with social justice and health (Bond & Singh, 2020; Schultz, 2020a).

The national priority for chronic diseases, including kidney health, is to focus on holistic and sustainable health services (Health, 2021). These health policies incorporate treatment options for health and endorse creating adequate time for the decision making and treatment planning stages, in collaboration with patients. (Dudgeon et al., 2023).Under the Closing the Gap initiative, there is a commitment to addressing health and the life expectancy gap of 10-20 years (Commonwealth of Australia, 2024).The focus is on facilitating planning and decision-making for individuals, with the aim of slowing the progression of the disease. This process is clearly outlined in the CARI Kidney Health guidelines and policies (CARI Guidelines2022) .

Part of the process of increasing patient engagement in planning and decision making includes engaging in ways that need an Aboriginal and Torres Strait Islander patient's needs; specifically, ensuring that culturally responsive and supportive ways of working are used (Nutbeam, 2000; Nutbeam & Lloyd, 2021).

The Purple House (House, 2024), is a good example of culturally supportive policy and practice for Aboriginal and Torres Strait Islander people living with CKD. It is a non-profit organization that integrates access and equity for Aboriginal and Torres Strait Islander people with CKD. It is a place where patients can learn how to engage and participate in programs and acquire skills and knowledge about CKD, including traditional approaches to care, such as healing and bush medicine. They can acquire skills to practice and to make bush medicine and to socialise and access extra support for their kidney health matters. Additionally, they intertwine both non-Indigenous and Aboriginal and Torres Strait Islander ways of treating CKD.

The CTG policy recognises and addresses the gaps and discrepancies in health status between Aboriginal and Torres Strait Islander people and the wider population of Australia. The aim and objective of this policy is to "achieve equality in health status and life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous in Australians by 2030" (Calma, 2009; Commission, 2023). It is important to try to eliminate negative aspects and negative experiences that contribute to poorer health outcomes for Aboriginal and Torres Strait Islander people and that there is a relationship between the social disadvantages that continue to affect their overall health status and access to medical services and health professionals. This has created numerous disparities within the health system. This is also influenced by culture and identity which reflects the value of health and treatment, and where many Aboriginal and Torres Strait Islander people may be systematically affected by the medical sphere in a way that does not always recognise the connection to Country, community, culture and language (Bernardes et al., 2018)

This research explored areas where health outcomes can be improved through understanding underlying health conditions, particularly where the prevalence of other chronic conditions is increased. As discrimination and disrespect can impact the person's health of those accessing medical services, and the necessity for culturally appropriateness, and leadership by Aboriginal and Torres Strait Islander health professionals. These health professionals' have a crucial role in promoting advocacy and apply medical interventions to support Aboriginal and Torres Strait Islander people, in order to improve their health and outcomes (Dudgeon et al., 2023).

The importance of the cultural and social determinants with an ongoing emphasis on CKD health and wellbeing

It is important to consider the role of cultural and social factors in relation to CKD health and wellbeing. When we think about health, we need to remember that there are many various factors that can influence standards and outcomes. For example, it is interesting to compare the health of Aboriginal and Torres Strait Islander people compared with the rest of Australia society (Agency, 2023; AIHW, 2015; Hoy et al., 2010).

Many Aboriginal and Torres Strait Islander people live in rural, remote and isolated rural areas of Australia, where there may be inequalities and disparities in health services and access to medical care and treatment. It is therefore vital to acknowledge the role of social determinants, such as access to medical treatment, resources and economics are provided at the Commonwealth, State and Territory levels. The way distribution of funds, resources and services is available, this comes down to how the community and society interacts with health care and services, issues include negative aspects of discrimination and cultural biases, which can create disparities and disadvantage within health, and can significantly influence health outcomes (Kerr et al., 2024; Majoni et al., 2021; Sinka et al., 2021).. It is important to acknowledge the potential challenges, including negative aspects of discrimination and cultural biases due to past government practices. This may have contributed to creating inter-generational trauma and the flow-on effect that continues today, because of the health system, due to issues of trust or discriminatory measures. Therefore, services such as Aboriginal Community Controlled Health Services (ACCHS) and Aboriginal Medical Services (AMS), have been set up with the aim of eliminating and reducing discrimination and systemic racism tactics within health services and access to access medical services (Power et al., 2021). It is important to acknowledge the disproportionately high rates of an increased burden of diseases associated with chronic health conditions, such as increased prevalence in kidney health challenges and renal failure. This has led to the recognition where it is now a public health matter and is a national health priority, due to the high prevalence rates and mortality of CKD Aboriginal and Torres Strait Islander people and increased rates of CKD within communities.

The cultural context of accessing and using health care is important for Aboriginal and Torres Strait Islander Australians.

It is important to acknowledge the vital services provided across the Aboriginal Community Controlled sector, through Aboriginal Medical Services (AMS) or Aboriginal Community controlled Health Services (ACCHS), which include specific, culturally aligned Aboriginal and Torres Strait Islander health care and treatment. These services are designed to cater to the needs of Aboriginal and Torres Strait Islander patients and seek to encourage service engagement that meets specific health needs (Mackean et al., 2025; Pearson et al., 2020). Many services focus on having cultural awareness and equipping healthcare professionals with the necessary practices and knowledge for appropriate cultural engagement (Baba et al.,2014).

Aboriginal Community-Controlled Health Services and kidney health

Aboriginal Community Controlled Health Services (ACCHS) were established with the aim of providing culturally appropriate healthcare within the community, largely in response to the increase in negative experiences and challenges Aboriginal and Torres Strait Islander people faced in the healthcare system and in primary health practices (Pearson et al., 2020; Sinka et al., 2021). ACCHSs are leading health care providers and part of the primary health provider networks, working with the Aboriginal Medical Board (AMB) to improve higher chronic health conditions and illnesses that are not being managed appropriately within the mainstream health services (Baba et al., 2014).

While it is important to note that each State or Territory has its own ACCHSs, health policies and priorities, kidney health has been recognized as a national health priority, and the significance of early detection and culturally appropriate treatment is key (Sinka et al., 2021). ACCHSs are well-positioned to contribute to this effort by providing essential medical services and facilitating early detection, aligning with national focus on enhancing kidney health matters and a focus on kidney health and picking up on a decline in kidney function from a patient's medical history or results, and addressing renal failure.

Providing culturally sensitive and appropriate care (as defined by the needs of the patient) is key to best serving Aboriginal and Torres Strait Islander patients (Liaw et al., 2015; Liaw et al., 2019). This is where ACCHSs play a vital role in the primary health care and the clinical setting. ACCHSs also carries out comprehensive health checks for Aboriginal and Torres Strait Islander people, which indicate any underlaying health concerns or conditions to be managed and treated appropriately, making health and wellbeing a priority and importance to the person and community (Lakhan et al., 2022).

It is important to note that kidney disease is frequently recorded “as an additional diagnosis” in medical records or on the death certificates because kidney disease is often not recorded as the primary disease (Agency, 2023), with CKD often overridden by underlying health conditions such as cardiovascular disease (CVD), or diabetes which are often listed as cause of premature death (Agency, 2023).

ACCHSs provide care that is cognizant of social and cultural determinants of kidney health and seek to provide care in ways that optimise treatment for Aboriginal and Torres Strait Islander people (Gorham et al., 2024; Poirier et al., 2024; Sethi et al., 2022).

Chapter Summary

In summary, it is important to understand past practices of government policies relating to Aboriginal and Torres Strait Islander people and communities. I have provided important context with Aboriginal and Torres Strait Islander health. Where this could be seen as two different worlds, as Aboriginal and Torres Strait Islander people have poorer health outcomes than the general population of Australia.

Recognizing that Aboriginal and Torres Strait Islander people face an increased burden of disease associated with chronic health conditions, this is now a public health issue and national health priority. While Australia's history is characterized by a silent history of colonisationcolonisation and government policies. This silent history continues with a silent disease that creates a shorter life expectancy gap and a diminishing quality of life, with discrepancies and disparities within the health system aimed at Aboriginal and Torres Strait Islander people have poorer health outcomes. In focusing on reducing inequalities, inequities and the different types of disparities that still exist. Health literacy, information, education and advice provide empowerment and allow for improved health outcomes and health status. It constitutes fundamental rights within the health system, where health information, education and resources for kidney health play a holistic role in improving health outcomes for Aboriginal and Torres Strait Islander people. Therefore, there is a great need to incorporate health literature, information, health education and advice to improve the health and wellbeing of Aboriginal and Torres Strait Islander people and communities.

In the next chapter, I will provide a literature synthesis relating to Aboriginal and Torres Strait Islander renal health and some CKD health literacy context.

Chapter 3: Literature related to renal health

Kidney Health fundamentals

Irrespective of the underlying cause of kidney failure, a diagnosis is made when two or more of the following conditions are present over a period of at least three months: The estimated glomerular filtration rate (eGFR) is calculated from the pathology results or by measuring the glomerular filtration rate (eGFR) and determining a value of less than 60 ml/min/1.73 m². Alternatively, the diagnosis may be made if there is evidence of kidney damage for a period exceeding three months, or if there is evidence of kidney damage such as the presence of protein in the blood or blood within the urine. In all cases, a urinary tract infection (UTI) must be excluded in all cases. Additionally, any structural abnormalities observed in the kidney scans and tests, as well as any pathological abnormalities identified through renal biopsy, should be considered (Hussain et al., 2023; Levin et al., 2023; McCauley et al., 2022) .

The primary clinical indications where it has been observed that patients may present with a range of signs and symptoms include fatigue, anemia, dyspnea, nausea, alterations in urine volume, and hypertension. It is therefore crucial to facilitate early detection, ensure the provision of appropriate health information and literacy, and implement effective management strategies to slow down the progression of the disease, as this may result in end-stage renal failure (K. H. Australia, 2024a, 2024b; Borg et al., 2023; Daugirdas, 2019). In the event of inadequate renal function or filtration, creatine accumulates in the blood. The filtration capacity of the kidneys is assessed through the glomerular filtration rate (eGFR), which provides insight into the rate or flow of filtration. This is calculated and documented in the pathology results of the blood test (Hussain et al., 2023; Levin et al., 2023; McCauley et al., 2022).

Aboriginal and Torres Strait Islander context for renal health

In the context of Aboriginal and Torres Strait Islander health, when an Aboriginal or Torres Strait Islander individual accesses ACCHS for a health check-up or visits their doctor for a full blood test, the results of these tests are included in the individual's pathology results. The full blood test is designed to detect the function of the kidneys, and individuals considered to be at risk groups within society are recommended undergo kidney checks (Coombs et al., 2023). However, it is important to note that the conditions are more prevalent among Aboriginal and Torres Strait Islander peoples, individuals with pre-existing cardiovascular disease, those with a history of hypertension, those belonging to socio-economically disadvantaged groups, individuals aged 60 and above, and those with a family history of kidney disease. The presence of kidney damage is indicated by albuminuria, proteinuria, and haematuria, as evidenced and indicated by pathology results, is an indication of damage (Hussain et al., 2023; Levin et al., 2023; McCauley et al., 2022). It is therefore important to note that a decline in kidney function can also occur because of environmental factors, the use of certain medications, extensive surgery, violence, and sporting injuries (Harrison et al., 2021).

CKD is a national health priority in Australia. CKD is included in the category of chronic health conditions and diseases. It is estimated that the overall burden of CKD is 7.8 times higher in Aboriginal and Torres Strait Islander people in Australia than in non-Indigenous Australians (Agency, 2023; AIHW, 2015; Hoy et al., 2010).This is where the prevalence of CKD is 2.1 times higher among Aboriginal and Torres Strait Islander communities in

Australia compared to non-Indigenous Australians. The data presented in this article are based on the National Health Measurement Survey (NHMS) 2011-2012 and the 2012–13 National Aboriginal and Torres Strait Islander Health Measures Survey (Agency, 2023). However, it should be noted that there are instances where health information may be withheld, denied, not provided, or is confusing, or information that is contradictory because of the way the information or advice is conveyed to patients. Furthermore, Burke emphasises that patients often lack awareness and require enhanced health literacy, as well as supplementary assistance and resources (Burke et al., 2014) . Consequently, it is crucial to possess adequate health literacy, as this can influence an individual's overall health and well-being, in addition to having access to effective support from family and community to effectively manage their condition.

Cormick et al. (2022) describes a personal experience of CKD for an Aboriginal patient and suggests a novel approach to the management of CKD, emphasising the importance of a holistic approach to treatment. The article identified potential cultural challenges and suggested we must look at the whole person, not just the presenting CKD. This article has identified cultural difficulties experienced by Aboriginal patients as they move away from Country for treatment. It has highlighted the importance of decolonisation and the biomedical model in healthcare, highlighting their potential to restrict the scope of care within the health system. This article also explores cultural biases and the greater need for cultural awareness, and the challenges posed by medical jargon and cultural barriers in the clinical setting.

Health literacy on kidney health:

Health literacy is both about the capacity a patient has to best understand their kidney health, and about the types of information made available to patients to increase their health literacy related to CKD. It indicates that effective chronic disease management can slow disease progression, enhance quality of health and quality of life. If CKD is not managed effectively, it progresses to increase rates of comorbidities and ultimately leads to mortality. This is a prevalent and increasing phenomenon in Aboriginal and Torres Strait Islander communities. Evidence suggests improving the quality of kidney health information, education, advice, communication, and increasing patient health literacy, has scope to contribute to improving the health of Aboriginal and Torres Strait Islander people using well informed management, and self-efficacy (Lin et al., 2023; Lin et al., 2016). It is important to note that there is a connection between kidney health and several other conditions including renal failure, kidney failure, kidney disease, and chronic kidney disease (CKD). In addition, it is worth considering the link between kidney health and other health issues, including infections, sepsis and hypertension, cardiovascular disease and diabetes (Arici, 2014; Borg et al., 2023; Tunnicliffe et al., 2024). Co morbidities are more common among Aboriginal and Torres Strait Islander people (Gorham et al., 2022; Rheault et al., 2021) .

Increasing participants' understanding of their kidney health and their health literacy is considered to be an enabler of better health outcomes (MacAskill et al., 2022; Meuleman et al., 2024).Building CKD health literacy of patients in ways that allowed them to engage information into their daily lives is considered key to improve their CKD and health outcomes (Dominello et al., 2021; Gotlieb et al., 2022; Pitt et al., 2020; Recabarren, Van Zwieten, et al., 2024; Willows et al., 2022) .

In the pursuit of measuring Kidney health and CKD progression (MacAskill et al., 2022), a variety of instruments are at our disposal for assessing health literacy, information, education, resources and advice(Liu et al., 2020; Urstad et al., 2022) .In adopting a universal approach to health literacy, it is essential not to assume a one size fits all, noting diverse needs require bespoke understanding (Hughes et al., 2023) . It is understood that health literacy encompasses a range of areas, including understanding, reading, applying, comprehending information, analysing the information provided, clarifying, and interpreting symbols and pictures. It also extends to making decisions and planning and being proactive, effective communication, and good practices in navigating the health system to acquire quality of health and quality of life. In addition, it may be able to slow down the progression of CKD and make lifestyle modifications or other changes (Langham et al., 2022). As (Calleja et al., 2023; Tesfaye et al., 2024) have suggested health literacy, information, and education should prioritise enhancing health and slowing the progression of the disease through lifestyle modifications (Calleja et al., 2023; Tesfaye et al., 2024).

It is imperative that health literacy is addressed in a culturally inclusive manner, screening for health literacy is conducted in a culturally sensitive and appropriate manner, as this can lead to improved health outcomes. (MacAskill et al., 2022) has highlighted the crucial relationship between health literacy and the utilisation of health services, particularly for Aboriginal and Torres Strait Islander people, where low health literacy can result in limited access to information.

It is essential to consider the development of appropriate CKD assessment tools that could potentially enhance Aboriginal and Torres Strait Islander people and communities, in alignment with appropriate methodologies such as Yarning. This approach has the potential to maintains cultural practices that could benefit patients, while simultaneously fostering good communication practices and high-quality health literacy for effective chronic disease management and optimal patient health outcomes (MacAskill et al., 2022). Considering the absence of a dedicated health literacy tool for Aboriginal and Torres Strait Islander patients, it would be beneficial to explore ways to address this gap (MacAskill et al., 2022). MacAskill et al. (2022) underscores the importance and significance of health literacy and its correlation with social and cultural determinants of health. The article raises thought-provoking and crucial questions about the link between low health literacy and poor patient outcomes. It is essential to address deficiencies in the existing health literacy literature gaps and the appropriateness of current assessments, with a view to better meeting the complex health needs of Aboriginal and Torres Strait Islander peoples.

Langham et al. (2022) insight into health literacy, prevention, education, and information, and it suggested that health literacy is the ability to access and comprehend information to make informed decisions. Where disparities exist, it is recommended that education must be codesigned with patients and policymakers. This article explores and looks at how social media can help patients access education, information, and health literacy skills, with the aim of improving their health. It suggested that health literacy must be interactive and incorporate the input of health professionals and policymakers, and that culturally appropriate knowledge is crucial in empowering patients. It is suggested that kidney policy and advocacy can facilitate a change in approach at the jurisdictional level, which is crucial in improving health literacy. Good communication and improved health literacy can help to bridge the gap in understanding the burden of CKD in the community.

Nash and Arora (2021) examines the experiences of Aboriginal and Torres Strait Islander people and the associated health outcomes, with a particular emphasis on enhancing health literacy, self-determination and autonomy. The article addresses health literacy and its impact on health outcomes, evaluating interventions to enhance health literacy among Indigenous Australians. It covers nutrition, lifestyle modification, Aboriginal and Torres Strait Islander community involvement, and health literacy. This is important as lower health literacy is often a significant barrier to effective CKD management in some communities. The article looks at the importance of skills acquisition in achieving better health and addresses the role of environmental, political, and social factors in health promotion. It also discusses the cultural health belief system and ways to improve cultural literacy. It goes on to examine the complex needs of individuals and populations, and the impact of colonialism and the Closing the Gap initiative.

Management, self-efficacy and kidney health:

The management of kidney health can become complex, with everyone requiring a bespoke approach to meet their specific health needs (Kerr et al., 2024; Majoni et al., 2021; Sinka et al., 2021). As the disease progresses, additional changes and modifications, or interventions may be necessary. Therefore, CKD should be managed as a collaborative process, with appropriate health literacy, information, education, advice and resources, such as interventions, being made available (Jardine et al., 2017; Meuleman et al., 2024; Valizadeh-Haghi et al., 2023). Furthermore, individuals must be equipped with the capacity to comprehend and regulate the disease process, as well as to integrate lifestyle modifications to ensure the maintenance of optimal health and quality of life (Schrauben et al., 2022). It is important to consider and have an understanding of the fundamental principles of: kidney progression, signs and symptoms of the kidneys and how it relates to anatomy of the body, diet, nutrition and fluid intake (Naber & Purohit, 2021). The interaction of the body and the kidneys, including the pathology and the interaction with the kidneys within the blood, from estimated glomerular filtration rate (eGFR) to creatinine or potassium. Furthermore, it would be beneficial to consider the complexity of medication on the kidneys and the effects of medication on the kidneys must be considered. All of these factors are based on management, self-efficacy and slowing down the progression of the disease process, as well as the willingness to engage and participate with health professionals and vice versa (Australia, 2022).

Kelly et al. (2022) explore ways to support the health of Aboriginal and Torres Strait Islander people living with CKD, as informed by Aboriginal and Torres Strait Islander patient perspectives. The research identified areas of systematic racism and indirect labelling, highlighting the potential of treatment to save lives and acknowledging the specific needs of Aboriginal patients. They highlighted the value of renal care pathways and suggested that maintaining health, informed choice, improving health, and culturally secure care may be effective strategies for ensuring appropriate renal healthcare for Aboriginal people. It highlights the value of advocacy and leadership in the community and the importance of a comprehensive understanding of the disease and an awareness campaign. The objective is to ensure survival, understand kidney health, enhance health literacy, and disseminate information to the community. Healthcare professionals must understand the importance of treatment access and the barriers. The article presents a case for improving pathways to transplantation and medication as part of a holistic approach to health. It is important to acknowledge the challenges faced by patients, including the lack of diagnosis, and the importance of early detection. Furthermore, there is a lack of clarity regarding treatment options and the associated burden of home dialysis. It is suggested that the social determinants of health be given due consideration, as well as the challenges patients may face in accessing specialist care, the complexities of transplantation and the uncertainty patients may experience when attempting to navigate treatment options. It is also proposed that the significance of peer education and support be emphasised, as well as the necessity for cultural awareness and safety.

Where are renal patients getting their information?

Patients are accessing health information from various sources, including pamphlets. Sirimalla et al. (2023) explored the educational aspects of chronic kidney disease and the use of leaflets.   The article highlighted the availability of diverse educational materials online, though these may not always be reliable or accessible, necessitating and highlighting the need for adaptation. Leaflets are designed to educate patients. Patients often prefer leaflets as they are convenient and accessible, facilitating knowledge consolidation. This study utilised the 'Baker Assessment' to assess and evaluate patient knowledge before and after the provision of leaflets.

Online sources offer reliable resources, including Kidney Health Australia (Australia, 2025), with section where users can submit queries and request additional resources via email. Patients are also using a variety of online platforms, including search engines, social media (Biruete et al., 2022) and other online resources to access information and engage in networking. There are a variety of resources are available for patients' seeking information on kidney health (Kidney Health Australia, 2025).

Several resources aim is to improve kidney health literacy by using simple language, for example “Dialysis involves the removal of water and waste, as well as the filtration of toxins and excess fluid” (Kidney Health Australia, 2025). This website provides a straightforward explanation of different hemodialysis treatment, as well as an overview of the available treatment options, including peritoneal dialysis. It also offers a simple yet comprehensive guide to nutrition and kidney disease, with meal ideas and recipe books. Additionally, the website provides supplementary resources and booklets tailored to the needs of Aboriginal and Torres Strait Islander communities, featuring traditional foods. This website is designed with the needs of both kidney patients and health professionals in mind. It offers additional resources and support, as well as a forum for patients to ask questions.

Furukawa et al. (2023)puts forward the idea of using presents the use of online patient education videos as a means of engaging with health literacy and information for the purpose of managing chronic kidney disease (CKD). The information presented in the videos is designed in such a way that patients can comprehend it, apply it to their own lives to make behavioural changes, and modify their actions accordingly. Patients reported that they found the lack of visual aids has been a challenge, as they have found it difficult to fully understand the concepts presented and identified themes that were conveyed.

Isautier et al. (2022) explore the potential use and efficacy of the SUCCESS app, developed and created with the aim of supporting users with CKD and to facilitate positive outcomes for patients. The app, SUCCESS, is designed to assist and support patients from diverse backgrounds. Considering the intrinsicses involved and the complexity within health literacy information and education, a theoretical model is needed. The app teaches skills and helps users understand information, to facilitate comprehension of information. The aim is to empower individuals to manage themselves effectively and make informed decisions and equipping them with the necessary skills and knowledge to do so effectively (Muscat et al., 2021). The app has animated videos on various topics, including communication with healthcare professionals, shared decision-making, online information, and medication. The app contains a variety of information on dialysis and treatment options. Its objective is to cultivate competencies, particularly in decision-making and effective management of treatment plans. Other areas of significance in behavioural change include self-management of diet, fluids, medication and physical activity.

The study also explores a range of outcomes, including a nutritional status tool that measures weight, intake, symptoms, functional status, disease state, metabolic stress, and nutritional physical examination. It also considers chronic conditions, using qualitative data on key performance indicators.

Colbert et al. (2018) highlighted the growing importance of the increasing utilisation of social media platforms and mobile applications, observing from the highly specialised nephrology community and their expanding resources. There was a growing interest in social media platforms as a means of providing information and education to patients. This article reviewed the social media, educational, and resources used within the nephrology area to educate and disseminate information. The tools include Twitter, visual abstracts, videos, and blogs. The article also explored the potential of free open-access medical education (FOAMed) tools to support the platforms of social media and the nephrology community.

Also exploring health apps, Zwi et al. (2022) suggest apps must be sustainable within the e-health platform. They must improve health literacy, self-management and decision-making among hemodialysis patients and the culturally diverse in Australia and the health systems. The apps must be sustainable and offer health literacy-informed and promote "active participation in hemodialysis, self-management and decision-making" (Zwi et al., 2022). They must promote culturally diverse, and culture focus on 'low health literacy groups'. However, the apps need to be specifically personalised and continually updated.

Chapter summary

This chapter presented a synthesis of the Aboriginal and Torres Strait Islander CKD context, and the role CKD literacy plays in managing CKD. It synthesises some of the key health literacy initiatives aiming to support Aboriginal and Torres Strait Islander people living with CKD and explores some of the source of health information available to patients. It also highlights important gaps in the literature related to patient experiences, to which this research speaks.

In the next chapter I will present my methodology and methods.

Chapter Four: Methodology and methods

This chapter describes the methodology and methods used in my research that have guided my research, when working with participants who have identified as Aboriginal and Torres Strait Islander people with kidney failure or CKD.

My research recognises and listens to the voices of Aboriginal and Torres Strait Islander people, their perspectives and lived experiences through Yarning. By applying Indigenous methods, such as Yarning, I use a collaborative approach that is culturally sensitive and culturally appropriate, as I listen to the participants lived and shared experiences.

In this chapter I will outline the overarching theories that informed my research (Indigenous Standpoint Theory, Decolonisation Theory and Health Literacy Theory). I will describe my methodology and methods, the ethics application process, recruitment, data collection and method of analysis.

Guiding principles of my research

Aboriginal and Torres Strait Islander Research principles

Aboriginal and Torres Strait Islander people have been subject to countless research studies, with many not positioning the Aboriginal and Torres Strait Islander voice at the center of research, and often without any sense of reciprocity. Thankfully new investment in improved research ethics has resulted in a positive shift in how research is planned and undertaken. Current ethical guidelines for research with Aboriginal and Torres Strait Islander Australians acknowledge the vast cultural connections, traditions, knowledge and experiences that Aboriginal and Torres Strait Islander people hold and recognise the importance of authentic, engaged research processes (AIATSIS, 2020; Luke J Burchill et al., 2023; Health & Council, 2018a, 2018b; Kennedy et al., 2025). I feel fortunate that my own research was done when these ethical guidelines were available and respected by human research ethics committees. As such I have been guided by the National Statement on Ethical Conduct in Human Research (Council, 2025). Importantly I have been guided by researchers who are Aboriginal and Torres Strait Islander researchers committed to upholding high standards of ethical conduct in Aboriginal and Torres Strait Islander research. While I also have had excellent guidance from non-Indigenous researchers, the Aboriginal and or Torres Strait Islander researchers provided a cultural perspective and insight that ensures cultural awareness and respect throughout the research process. Importantly they guided me and my research to ensure it would contribute to making meaningful changes and that has capacity to benefit Aboriginal and Torres Strait Islander people and communities (Kingsley et al., 2018).

Theories informing my research

As an Aboriginal and Torres Strait Islander student researcher, I wanted to engage and learn from the participants experiences, and my research has allowed me to focus on the voices and experiences of Aboriginal and Torres Strait Islander people living with kidney disease. I was curious to understand if the information and education from the health professionals was helpful or useful to the participants as they navigated their own kidney health journey. As an Aboriginal and Torres Strait Islander student researcher, it felt natural to me to use Indigenous methods as I sat and listened to participants lived and shared experiences (Jennings et al., 2018). My approach is to present an Aboriginal and Torres Strait Islander perspective within my research, in using best practice principles that are culturally sensitive and respectful (Muscat et al., 2018; Sherwood, 2013) . However, given that my research is being conducted for a Master of Philosophy degree at a Western higher education institution, it was also important for me to apply some of the practices and theories of knowledge from the Western bio-medical sphere, but I focused on being informed by theories advocating for research done in respectful ways, and in ways of knowing, being, and doing that aligned with me as an Indigenous researcher (Bullen & Flavell, 2022; Gatwiri et al., 2021; Rigney, 2006) .

Indigenous Standpoint Theory

My research has incorporated literature on Indigenous Standpoint Theory (Nakata, 2007b), as I have taken the position as Aboriginal and Torres Strait Islander researcher, researching issues related to the experiences of Aboriginal and Torres Strait Islander people. I have been careful to incorporated theories of knowledge. I have sought to apply methodologies that make cultural connections from an Indigenous Standpoint that intertwining the diverse knowledge exchange from the participants and myself as a researcher (Ryder et al., 2020).

In applying an Indigenous Standpoint I have been able to acknowledge and appreciate the connections between Indigenous people and to bring a cultural engagement lens to the interaction and engagement with the participants' knowledge and experiences of their CKD journeys, the health system and their health professionals. Indigenous Standpoint Theory reminds me of potential power imbalances in research between researcher and participants and encourages me to work in ways that reduce that imbalance through engaging with both research methods and cultural methods. Indigenous Standpoint Theory also reminds me of similar power imbalances in the healthcare system, often between patients and their treating healthcare professionals. This is where there needs to be a decolonisation approach to the healthcare systems, particularly between patients and health professionals, and the potential benefits of decolonisation principles to bring meaningful change due to the systemic inequalities and equities that exist within the Western research spheres (Keikelame & Swartz, 2019) . It is suggested that the adoption of research approach informed by an

Indigenous Standpoint will create change in this space as it will allow for connection with the knowledge exchange and research experiences from an Indigenous Standpoint perspective, rather than relying on or defaulting to a dominant Western research worldview and practice (Rissel et al., 2022) .

Where the Indigenous Standpoint acknowledges the empowerment of Aboriginal and Torres Strait Islander peoples and the struggles from the past, it centrally positions Aboriginal and Torres Strait Islander voice in research. The Indigenous Standpoint theory invites us to consider cultural perspectives, life experiences and insights through the lens of one's own position and worldviews (Braun & Clarke, 2006; Nakata, 2007a, 2007b) . It also allows has the potential to embrace cultural conceptual frameworks and ways of knowing, being and doing, integrating them into research (Moreton-Robinson, 2013) . From an Indigenous epistemological position, there is potential to reduce power and control in research, as researcher (me) and participants engage with cultural ways and through research processes (both of which are intertwined) (Moreton-Robinson, 2013; Rigney, 2006; Thomson, 2024).

Indigenous Standpoint Theory engages with the 'cultural interface', the space between the Western knowledge sphere and Indigenous knowledges (Moreton-Robinson, 2013; Nakata, 2007b). In my own research, adopting an Indigenous Standpoint has allowed and supported me to embed cultural ways and perspectives into my research. I believe that this has contributed to making my research meaningful for participants, with the hope that it will lead to positive outcomes that will benefit future CKD health education and information support for Aboriginal and Torres Strait Islander patients. An Indigenous Standpoint allows me to ensure Aboriginal and Torres Strait Islander participants are empowered through their participation and feel safe to express and share their lived experiences. It also ensures self-determination through their voices and sharing lived experiences, choosing what they want to talk about within the Yarning process. Respecting Yarning this way, within a research context, also allows for a collaborative approach that involves engagement in respectful ways (Bullen & Flavell, 2022).

My research engages specifically with Aboriginal and Torres Strait Islander people living with kidney disease or CKD. As an Aboriginal and Torres Strait Islander researcher, my approach is guided by a desire to foster meaningful and respectful engagement, with a view to enhancing our understanding of what supports and benefits patients as they navigate through their CKD journey. My positionality in the research, informed by an Indigenous Standpoint, seeks to gently transition from the historical past practices that have dominated Aboriginal and Torres Strait Islander research to a more culturally safe and responsive way of undertaking research. An example of this is my acknowledgement that the participants hold the knowledge in the research process, and I, as a researcher, need to listen, engage, and ensure the shared words are heard and valued as part of the research process. My research incorporates respectful engagement and dialog, underpinning by an Indigenous perspective with a view to empowering participants by acknowledging their cultural connections and maintaining respectful practices and respectful ways and practices throughout the research (Muller et al., 2019; Nakata, 2007b).

Decolonisation Theory

Decolonisation Theory(Jones et al., 2023; Sherwood, 2013; Smith, 2019) in research aims is to achieve equity, social justice and fundamental human rights. As a theory, it has been instrumental in keeping me aware of the past and ongoing discrimination, systemic racism and government practices experienced by Aboriginal and Torres Strait Islander people in systems like education, law, health and in research. Decolonisation theory reminded me to ensure any work I do should contribute to redressing the wrongs of colonisation and the ongoing effects of colonisation and ensuring that my approach to research should not perpetuate the injustices experienced by Aboriginal and Torres Strait Islander people (Mackinlay & Barney, 2014).

In the spirit of decolonisation in research, it is important to acknowledge both the Western research paradigms and to acknowledge and value ways of Aboriginal and Torres Strait Islander ways of knowing, being and doing. It is essential that this process is led by Aboriginal and Torres Strait Islander people for meaningful change to take place (Bullen & Flavell, 2022).

In the pursuit of impact, it may be beneficial to consider integrating decolonisation methodologies into our research, with the aim of acknowledging the opportunities presented by applying an Indigenous worldview. While this theory informed my research planning and approach, I also explored and made connections with the potential decolonisation presents to practices and approaches in health care settings, with a focus on cultural inclusion, cultural awareness, cultural sensitivity and respectful engagement. In creating a decolonised discourse and approach health care practices, collaborative partnerships, access, and respectful engagement could be possible in health care. I believe that, given the oppression and systemic discrimination and racism in the past, in both research and health care settings, Aboriginal and Torres Strait Islander people should be in leadership roles in any process of decolonisation (without carrying the entire burden of the task) (Downing & Kowal, 2011; Fernando & Bennett, 2019; Sherwood, 2013; Smith, 2019).

My research focuses on the importance of incorporating Aboriginal and Torres Strait Islander knowledge and lived experiences. I have endeavored to apply decolonisationcolonisation principles and practices, front and center, to empower Aboriginal and Torres Strait Islander people, through a proactive approach to research. I have done my utmost to ensure that my methodology and methods show respectful engagement, and central positioning of Aboriginal and Torres Strait Islander leadership and participation (Bessarab & Ng'Andu, 2010; Bullen & Flavell, 2022; Dudgeon et al., 2023; Kennedy et al., 2022; Sherwood, 2013).

Health Literacy Theory

The exploration of Health Literacy Theory (Logan & Siegel, 2017; Nutbeam et al., 2018) has been a journey of discovery as it has the potential for enhancing individuals' understanding and comprehension of their health through appropriate educational resources and effective communication. While the primary focus on this project is not on the engagement of health literacy, my learning has been deeply influenced by the various types of health literacy theory. My personal journey and own lived experiences as a career of a CKD patient showed me there are often missed opportunities to enhance patient experiences and knowledge through effective improved information sharing. When patients are not receiving the appropriate information or it is not individualised, this area can become complex, but it with patients potentially either not being fully informed, or not fully engaging with the style or level of health communication shared with them. My awareness of health literacy theory has assisted me to remain mindful of the diverse needs' patients have concerning what information they need, want or receive. It has also helped me to understand the possible challenges faced by patients and their health professionals, as they attempt to request, share, and understand health information related to their CKD journeys.

Research design

As a researcher, I have attempted to take on a culturally sensitive and respectful approach with my research. I have listened to voices from Aboriginal and Torres Strait Islander patients, to hear their lived and shared experiences and perspectives. I have allowed for empowerment through acknowledgment of their situation and the circumstances related to the health information received throughout their CKD journeys. I have tried to ensure that the design of my research gives the participants power to be heard and to ultimately create meaningful and respectful changes that enhance cultural inclusivity.

I was keen to use collaborative and participatory research methods from a platform that Aboriginal and Torres Strait Islander people considered to be culturally appropriate. I planned that my main method for data collection was to be using Yarning (Bessarab & Ng'Andu, 2010) to maintain equality, encourage two-way information exchange and to create a culturally familiar and responsive data collection approach. Yarning would also allow to center lived experiences and use a decolonisation approach (Mackinlay & Barney, 2014). While I was aware that my research degree was situated within a Western research institution, I was keen to explore ways to ensure that it did not always default to Western ways. In this regard, I designed a project that honored Aboriginal and Torres Strait Islander epistemological and ontological principles (Ryder et al., 2020) . My research design, which focusing on the use of Yarning as a data collection method (Bessarab & Ng'Andu, 2010), was intended to be supported important relationship building and the establishment of connections with culture between myself as an Aboriginal and Torres Strait Islander researcher and the research participants (Bullen & Flavell, 2022; Murrup-Stewart et al., 2021; Shay, 2021).

As an Indigenous researcher, my research design draws on Indigenous and qualitative methodologies. My research method is based on Yarning methods, that enabled me to listen to the participant and to engage with the participants experiences as an Aboriginal and Torres Strait Islander researcher (Bessarab & Ng'Andu, 2010; Sharmil et al., 2021). My research has also been guided by Indigenous guidelines and practices has allowed me to enhance on my project and connections with participants by integrating cultural connections, cultural respect and respectful ways (AIATSIS, 2020; L. J. Burchill et al., 2023; NSW, 2023).

Cultural protocols and Aboriginal and Torres Strait Islander ethics

Engagement with the participants was based on respectful relationships and cultural sensitivity, as it is always important to build a rapport with the participants, especially when the research contains sensitive information about their health journeys. The Yarning session within the interview allowed the participant to feel comfortable and to be open and to become safe within a research context. Therefore, it was important to uphold my Indigenous methodological approach and practices important to this research (L. J. Burchill et al., 2023). My research worked in with the participants who chose a time and day that suited them for the interview, to participate and had control over what they chose to share with me. They also knew they had the right to stop or withdraw at any time. It is important to note that during my data collection phase several participants were hospitalised due to declining health, which resulted in delays to my research. My original plan was to have one research yarn with each participant, but it was very important for me to respond to the health needs of the participants, and at times this meant lengthy delays before they were well enough for me to return to recommence data collection with them. I did my best to always uphold and hold respect for the participants needs. It is also important to note that the Yarns were based on conversation and allowed to have open questions and to be answered differently from each participant, as each participant's experiences and journeys were different. The participants kindly agreed to be recorded, which allowed me to listen and to clarify any situation. It also meant that if the Yarning interview needed to be paused (or stopped) due to the declining health, of the participants, there was a record of where we had gotten up to, and so returning to the data collection yarn later became much easier for the participant, who did not need to start again from the beginning.

The Yarning approach allowed me to show respect for the participants, and to maintain engagement and respectful ways and respectful communications was respectful to the participant that intertwined with my research methodologies (Cox et al., 2021). Some of the Yarning sessions took place in a hospital setting due to the nature of their health conditions and timeframe. Some participants who were dialysis patients found it easier to participate either face- to-face in the dialysis unit of a hospital, or on Zoom from within the dialysis unit whilst being dialysed. Due to the time it takes to be dialysed for treatment, and to maintain privacy for the participant I arranged separate rooms where the patient felt comfortable and ensured space was culturally and clinically safe for them to participating with my research.

Ethics approval

This research was conducted in accordance with the current ethical guidelines for research with Aboriginal and Torres Strait Islander people, including from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and National Health and Medical Research Council (NHMRC). (AIATSIS, 2020; Bobba, 2019; L. J. Burchill et al., 2023; Laycock, 2011; NSW, 2023)

This research was approved initially by The University of Sydney Human Research Ethics Committee (HREC) and under the ethics approval process (project number: 2106/23). Additionally, this research was also approved by the Aboriginal Health and Medical Research Council (AH&MRC 2106/23). These documents have been incorporated into my research, thereby ensuring that the core values that ensure the research that was undertaken ethically and with cultural continuity, as well as research that is culturally appropriate and respectful, were adhered to. Incorporating the values of fairness, reciprocity, responsibility and respect for the participants to engage with the research being conducted. In using culturally appropriate practices embedded into the principles of cultural inclusion were adhered to. I have endeavoured to ensure best practice principles were upheld throughout my research, as I worked with Aboriginal and Torres Strait Islander participants (Bobba, 2019).

Participant recruitment

The purposive sampling method used in this study was through networks of existing contacts in renal health, renal research and Aboriginal and Torres Strait Islander health research (Stratton, 2024) . The networks were connected to my two supervisors, each of whom had existing connections that enabled me to recruit participants, following an ethical process supported by the AMHRC ethics approval.

Purposeful recruitment included potential participants meeting the following criteria:

- The participant identified as an Aboriginal or Torres Strait Islander person.
- The participant has renal failure or CKD (in any stage); and
- The participant is over 18 years of age.

Due to the time constraints, and the limited word requirements of a Master's research project, primary data sources were limited to in-depth Yarning data collection with five recruited Aboriginal and Torres Strait Islander participants living with CKD (Atkinson et al., 2021). This study does not intend to be representative rather, it is qualitative research, that provides an in-depth understanding into the lived experiences of a group of Aboriginal and Torres Strait Islander participant who are patients and undergoing treatment through a range of services and providers, inclusive of Aboriginal and Torres Strait Islander and non-

Indigenous health providers, government and Aboriginal Community Controlled services, and they all live with a range of experiences related to their kidney disease or CKD (Stratton, 2024).

The ethics approved process of sampling and recruiting for this research was through ethics approved and culturally appropriate networking facilitated through my supervisors and their networks, with a focus on ensuring cultural appropriateness.

It is important to note that the recruitment phases were challenging, due to the existing number of health and wellbeing challenges frequently faced by people living with CKD, such as frequent hospitalization and unplanned health deterioration, the recruitment phase was challenging. Several interested participants were unfortunately unable to proceed after they had experienced an acute episode within their chronic condition. I kept my supervisors informed of the recruitment issues and difficulties and continued to respectfully recruit until I had the planned number. This process, however, took longer than planned, but importantly, it reflects the reality of the nature of CKD as a health condition and disease process. I always had to be mindful of potential participant limitations and be responsive to their needs and capacity.

The Participants

My research consisted of five participants who identified as being over 18 years of age, identified as an Aboriginal and or Torres Strait Islander Australians, and living with renal failure or CKD at any stage. I recruited three people who identified as female and two who identified as male. My research ensures names have been taken out, with all data de-identified because of privacy, confidentiality and ethical considerations; as such I refer to my participants as Participants 1 to 5.

Participant 1 is an Aboriginal and Torres Strait Islander man who is living with end stage renal failure, who is currently on dialysis and is hoping to move onto a donor list for a transplant. He advocates for respectful communication, education, self-management, self-advocacy and education. He lives in an urban location and is being treated in an urban health care setting. He needs to travel from into home into one of the major city hospitals specifically for Dialysis, and his wish is to have a transplant for a kidney, as he knows that he will have quality of life if a transplant can happen.

Participant 2 is an Aboriginal and Torres Strait Islander woman, who is on the transplant waiting list for a kidney transplant. She hasn't had education about transplantation and wants to know more. She was being treated in initially in a regional area health setting but has subsequently moved to an urban area health care setting and is having treatment at a major hospital in a city. Her need to be closer to health service meant a move for her entire family. She has a young family and wants to know more about CKD and how to improve her health status.

Participant 3 is an Aboriginal and Torres Strait Islander man who has received a kidney from a deceased donor. He supports other Aboriginal and Torres Strait Islander people in recognizing the challenges and barriers that Aboriginal and Torres Strait Islander people face as they live with CKD. He is being treated originally in regional area and moved for treatment to urban health care setting. However, because the way this State offers CKD treatment, he also has his treatment in another city, requiring him to travel frequently. He also advocates for Aboriginal and Torres Strait Islander people living with CKD as he has identified many cultural barriers, including language, misunderstood by health professionals. He is very concerned about appropriate use of language to ensure understanding and awareness of CKD and CKD treatment. He expressed worry over seeing other Aboriginal and Torres Strait Islander patients just agree to health professionals, without having the understanding or awareness of what they agree to.

Participant 4 is an Aboriginal and Torres Strait Islander woman who is on the kidney transplant waiting list and is currently on haemodialysis. She speaks many Aboriginal languages and can translate for health professionals. Her own CKD knowledge stems from family, and from family having kidney failure from diabetes. She has extensive knowledge about CKD treatment options and is being treated in an isolated regional health care setting, with fly in and fly out medical services.

Participant 5 is an Aboriginal and Torres Strait Islander woman who is on hemodialysis and is wanting a kidney transplantation (transplant) and is on the transplantation waiting list. She has a family history of kidney disease and diabetes and is being treated in an urban health care setting. She is currently receiving haemodialysis and is unsure about the disease process, wants to know more and wants to change her lifestyle and make modifications. However, during recruitment expressed that she has not had adequate or sufficient information education or advice to make these positive changes to improve her health.

Method

The importance of Yarning as a method, through conversations, and engagement with the participants and their experiences and insights is well respected as an Indigenous method (Bessarab & Ng'Andu, 2010). Yarning is a good and effective communication approach that is respectful, with Indigenous ways of, knowing, being and doing. As the participants all have different perspectives and self- awareness, but may also have shared understandings, this is generally overlooked within the Western ways and in the bio-medical sphere.

As Yarning methods are embedded into Aboriginal and Torres Strait Islander peoples' and cultural practices, it is important to note that this research is about having shared cultural connections through engagement. As part of traditional practices, Yarning is also about passing down knowledge and gaining new insights and perspectives. Yarning also allows for differences to be honoured and respected, as each of us has different perceptions and different journeys with the relationships formed between us. I have used Yarning as my data collection method to help build relationships with the participants and to ensure better and effective communications with Aboriginal and Torres Strait Islander participants (Jennings et al., 2018; Nilson, 2017). As an Aboriginal and Torres Strait Islander researcher, Yarning also allowed me to engage culturally within the interviews, listening to the participants voices and lived experiences and their journeys (Bessarab & Ng'Andu, 2010).

The questions that guided the Yarning interviews were approved as part of my ethics applications (See Appendix 1 and 2).. They allowed me to engage with the participants with approved practices, policies, and protocols based on respectful ways that were culturally appropriate and culturally sensitive for Aboriginal and Torres Strait Islander participants and respect their health condition and wellbeing.

Data collection

The Yarning interviews were either face to face or on a Zoom meeting, and were held at a library, in the hospital, or on zoom, depending on what best suited each participant. Some participants found it easier to do the zoom meeting at the hospital whilst having their treatment, as their treatment consists of sitting in a chair for approximately three hours, two times a week. There were several participants that came down with different illnesses during the recruitment period, and before the planned Yarning interviews. As a respectable measure, the interviews conducted later, re-scheduled to better suit the participant. Sadly, it is common for CKD patients to experience declines in condition and have acute episodes requiring intensive treatment. In most cases we could reschedule, but several participants, who had been recruited in the later stages, needed a longer period away from the research and as such we could not include them in the data collection. This was carefully explained to each participant, who understood the timeline and submission dates of my thesis. I carried out the interviews on my own but had the support and backing of my two supervisors, who were easily contactable if an issue or problem arose (especially during zoom interviews if technology became an issue).

The Yarning interviews were recorded, with participant permission, either on a recording device or on Zoom, and then later transcribed. Each participant was offered the opportunity to receive a copy of their own transcript to double-check their data, if they wished. This participant checking also gave participants a greater platform for their voice and allowed me to respectfully engage with them, giving full attention and allowing for respectful communication. It also provided an opportunity for the participants to reflect on their insights, perceptions, answers and experiences.

The Participants were given approved participant information sheets detailing the nature of the study, along with consent forms (See Appendix 1 and 2). They could stop or withdraw from the interview at any time during the interview process. The consent form needed to be signed before the interview took place and support was provided to the participants if they needed further support or information about the project if required. The interview was conducted on a voluntarily basis, and the participants were provided with reimbursement for travel, or any costs associated with participating, as per the approved ethics.

Analysis

I used the thematic analysis (Fugard & Potts, 2019) to analyse my research data, which I found to be an effective method. This involves re-reading the data from the interview transcripts, identifying patterns and consistency of themes and writing up the findings and relevant information. I found in using thematic analysis has enriched my research by identifying, organising, analysing and reporting themes within the data collection from the participants Yarning interviews (Fugard & Potts, 2019). I have led the analysis, with support and guidance from my supervisors.

The main process of this analysis was to extract data from the interviews. Based on the interview questions, the data specifically reflected the information resources, health education and advice received, understandings of the health information, literature and resources that were provided to them by health care professionals. Analysis also highlighted the types of information, health literature or resources that participants themselves accessed and found useful and beneficial. The analysis also captured participants' experiences, their journey within the healthcare system and setting, concerning the care, treatment options, education, information and resources provided to them. Participants also shared what enhances their knowledge, awareness and what supports them to make appropriate decisions and be fully informed, or information and education being given freely and not withheld.

I applied the six phases from Braun and Clarke (2006), when analysing the data, as it involves (i) becoming familiar with the data, (ii) coding, (iii) discovering and creating common themes, (iv) reviewing the identified themes and subthemes, (v) defining the themes and relevant themes with commonality (re-examining based on commonalities to identify the themes from the raw data) and (vi) writing up my findings. I have re-read the transcripts before coding, as this helped identify patterns when interacting and engaging with the data (Fugard & Potts, 2019). I then re-read the transcript to establish initial codes from the data descriptions and the analysis. I incorporated a reflexivity and reflective practice that has guided my research and in determining the main key themes and subthemes using thematic mind maps. My own reflexivity and reflections on lived experiences gave me an in-depth awareness to the data that has been obtained and written up in the participants own words so that they can share their lived experiences, and insights. It is my understanding that patterns and themes emerged from the participants engagement and participation, through the highly valued and respected participant data sharing.

Chapter summary

In this chapter, I described the theories that informed the development of my research. I have outlined my use of qualitative and Indigenous methodologies and described my use of Yarning as a data collection method. I have described the sampling process and participant recruitment and detailed my data collection and analysis phases. Importantly, I have acknowledged the participants, as they formed the basis of my research, and they made this research possible and provided additional themes for further research. In the next chapter I will present my findings.

Chapter Five: Research findings

Introduction

In this chapter, I will present my findings from the data analysis generated from the participants Yarning - interviews. My analysis presents two main themes, and subthemes. The data also highlights the complex nature of kidney health and what the participants' experiences are within the healthcare system. This data provides an insight into the participants' experiences and what they have been provided with, their understanding, awareness of their kidney health and how this relates to their health and the various types of; health information, education and advice that the participants have been given from health professionals. My research also allows for the participants' engagement, participation and insights on the types of health information, education, advice and how this has impacted on their decision making, planning and their kidney health journeys. The data analysis has allowed me to create themes and sub themes, with a view to enhancing the participants' voices and their lived and shared experiences.

Theme 1 is Challenges experienced when trying to access health education, and information, and comprises subthemes:

1.1 Withholding information regarding treatment options
1.2 Provision of Limited resources and support
1.3 Missed opportunities to delay disease progression
1.4 Power imbalances limiting sharing of information
1.5 Psychological impact following attendance.

Theme 2 is: “Advocacy for self”, comprising the subthemes:

2.1 Seeking own resources to supplement knowledge

2.2 Yearning for culturally appropriate care

2.3 Developing relationships through informal Yarning of shared experience.

Theme 1: Challenges experienced when trying to access health education and information

Participants were invited to share and describe their experiences with the types of information, education, and advice provided to them by healthcare professionals to improve their kidney health and awareness.

Participants were also encouraged to describe the complex nature of their kidney disease and the treatment options available or offered to them, or how they get a response from healthcare professionals. Participants were also invited to describe and discuss access and how they access kidney health information and education.

It is important to note that some participants' health problems presented, these health problems are complex or overwhelming in nature, as this created uncertainty about their health status and the potential for improvement. As well as how to improve their health condition, in slowing down the progression of the disease. It seemed that participants felt that health professionals did not spend time or collaborate with the participants for various reasons, resulting in the participants having more complex issues or problems. Where the participants felt that they did not have the knowledge or awareness, in understanding of their status of health or felt unable to improve their health condition and slow down the disease progression.

It was recognised by participants were aware that each patient has different experiences, different requirements and needs and therefore require different health information, education, advice and treatment options are available. Concerns were raised that health information, education and resources are not personalised, and that information, education or advice was provided to them from health professionals in a way that does not always meet their needs.

One of the main problems identified was the lack of access to reliable and good quality information, education, and advice, as this was seen as a barrier to improving their health and quality of life. Participants identified numerous challenges and barriers when navigating the health care system, including time constraints and the organisation of appointments with healthcare professionals, due to the nature of the system.

Subtheme: 1.1 Withholding information regarding treatment options

Some participants described how they felt their healthcare professionals had withheld information, or not shared health education publications, or adequate information about treatment options. While they were comfortable asking questions to obtain information from their healthcare professionals this required confrontation. One participant described having to “cause a big scene” because information and education was not provided freely, in a timely manner, was inadequate and did not meet their requirements or needs. This highlights the importance of the need to have autonomy and to self-advocate in accessing information, as expressed by Participant 1:

> Oh, ya, I am able(to get my own information), and feel very, very comfortable; I go to the renal outpatients down stairs, um cause a big scene, and then eventually my doctor will call me, so you can see what is going on, um, and then I can, like I’ve got the information, but until I go down stairs and cause a scene, I will not hear from that man for at least two months easily.

Having to “cause a scene” was considered an essential part of the information seeking process:

> …causing a scene – not a problem… because I’m the one doing the research into it, and it's not really given to me freely. I’ve got to. Like, once you go downstairs and make a scene – and say, “ok so you need to tell me why I have

> lost so much weight? If you can't advocate for yourself, well, you have really only got to do your own research to keep yourself on the straight and on the right track.
>
> (Participant 1)

Participants talked about the value of having options, having choices, and access to information, highlighting being informed, having educated, and how they felt information had been withholding or denied information or not given information. They felt that it has hinder their ability and did not help them make informed decisions about treatment options or planning. Several participants expressed feelings of being uninformed or misinformed or believed that healthcare professionals were knowingly making treatment decisions for them and not with them, as one participant expressed:

> I was just told, and I just pretty much went along, I was told what was needed for me.
>
> (Participant 5)

> I just went along…because I've never heard of peritoneal? What is that exactly?
>
> (Participant 4)

> From the beginning stages, nothing; They do give you bits, of paper... the little bits of paper because you have never done it before, it's a little bit confusing so, you are really just taking the advice of the doctors
>
> (Participant 1)

This highlights the inequalities within the healthcare system, where knowledge is needed to improve the health and wellbeing of patients from a holistic perspective, explained by one participant:

> I was going to go for the other one [referring to peritoneal dialysis] originally, but by accident the assistant to the doctor, happen to say to me, once you get an infection, in the tubing by the time it actually shows up on the exterior, that’s, it's too late, and you will probably end up dying from it, so the safest bet was to do this haemodialysis, ya, and knowing that was just by accident, so yeah, no one tells you really, what’s going to happen, what’s expected Blah, Blah, Blah, or how it does it, nothing, nothing, nothing, nothing really.
>
> (Participant 1)

It was suggested by some participant's believed that cultural bias led to the withholding of health information and believed that the treatment options were chosen by health professionals may have been influenced by concealed or hidden cultural biases that were not necessarily based on evidence:

> If you're from an Aboriginal or Torres Strait Islander family, the message that I was getting was that [getting a donor kidney] from a matching family member was not really acceptable, and it's not something that they would pursue. So yeah, I got it from a deceased donor. That is the reason why we stay on the list a lot longer. Why can’t we get family donations?
>
> (Participant 4)

> …I think that there is a generalization, because you’re Aboriginal or Torres Strait Islander, family members can't donate, and I said, hold on, my sister is 62 (years old) and she's not diabetic, and no heart condition, and you're telling me you won't even look at her? No, because she's Aboriginal and there's a risk that she has the natural tendency to diabetes, because of hereditary. I just thought that was a generalization, and that is a real stereotype. You need to assess every patient as an individual and that was one sort of thing I struggled with.
>
> (Participant 5)

Subtheme 1.2: Provision of limited resources and support

Participants described instances teaching may have been perceived as insufficient, inappropriate or inadequate. Which seems to have had adversely effects on their autonomy.

Participants indicated that healthcare professionals may deliberately choose to limit the information they provide, or simply to withhold it, which has led to a lack of trust between participants:

> …I was given bare minimum, bare minimum. A lot of the information that I found was just from asking other patients: what do they feel about this, that, or chasing the Australian Dialysis Facebook page, and then you can put questions in there and then they can get back to you and go, I found that this... blah, blah, blah, asked that and you can get varied responses, and then you can make your choice on it or take those choices to the nephrologist and go, "this is what I've been told …… and what do you think about that?", but the hospital staff, they don't really tell you anything, it's kind of like you turn up and they say " what are we doing today?", so you are learning as you are going. What about trust?
>
> (Participant 1)

> I'm never, being given any information unless I asked for it, and then? If they're not always 100% satisfied that is why, the information that they have been given to me, or the lack of information. So, generally I will... Look it up myself.
>
> (Participant 3)

> [hospital staff] didn't give…, they didn't give me a book, that's telling me about the kidney.
>
> (Participant 2)

Where information, education, or advice has been provided, it was not personalised, or it did not meet individual needs:

> It was nothing personalised, it was straight forward. I guess it was what they give to a lot of the patients, and it was not specifically for me.
>
> (Participant 5)

> Up here, (referring to treatment facility), they don't teach you how to read your bloods, and they're rarely give you a copy of your blood results. Unless you request it…but never have I ever received a copy of my blood’s, it is like a personal report is not relevant.
>
> (Participant 3)

It has been reported by some participants that the did not always received the level of support and communication with their healthcare professional regarding information, education, that they would have liked to have been given especially with advice and information:

> I feel like it should be something that should be discussed at the time of the transplant, and the patient and whatever, and even with the transplant action team, … tell me straight Information so that I can understand how long everything is going to be and take like, and that you're going to be in hospital for this amount of time, and this is the recovery, but nothing. And they didn't really mention anything about the follow up appointments after that. Why should a patient have to ask? You know. I just feel like it should be textbook, and it should be automatically given because they are doing transplants like every single, second day!
>
> (Participant 3)

> No support or info, they just wanna give us medications. Medications, okay. And the little, little machine for the checking sugar, and sometimes I take insulin for my stomach. That's for the diabetics, insulin. They just wanna give us medications but not much explaining.
>
> (Participant 2)

Subtheme 1.3: Missed opportunities to delay disease progression

One of the main issues identified by several participants was that some patients accept, agree, comply or were compliant, but do not fully understand due to language barriers or a lack of shared knowledge that could improve their own awareness of the disease process. These barriers often led to missed opportunities to make choices that could have slowed the trajectory of the disease:

> Once again, there is no Aboriginal or Torres Strait Islander Officer, again, no one to help interpreting. Again, they talk about the prevention, this is where key people should be in there, you've got mobs where English is their second language, and they don't understand, and they don't understand and agree with everything that the Doctor says, "what the hell does he mean? "
>
> So, you know, yeah if we had someone to help us better understand we might make choices to slow things down, in a good way.
>
> (Participant 4)

> … I say, "you didn't tell me this, you didn't tell me that, you didn't say that beforehand", umm, so, then I find out that I should not have done something, because it was wrong, and I should not have used google as a doctor… but my opinion is that it is easier to do that then to get a hold of you to make an appointment. It takes a long time, so I might make the wrong choices. I need to know more to be able to know my choices are wrong.
>
> (Participant 1)

It was suggested by some participants that there might be a need for appropriate intervention, information, advice education and resources to help them make lifestyle changes or modifications. It was also said that they had expressed the view that they had missed opportunities to be provided with more information and more time to develop their knowledge:

> So, the doctor warned me of this, and I wasn't seeing any major impacts, so I just ignored his advice I said I'll just sit down and listen and go to all appointments. But I was a heavy drinker and so I just continued on my merry way, but I said, well, if I listened to you all those years ago, I would not be in this situation. You said, all those years ago, make the change, that's right. But I needed more info to understand why I needed to change. I needed more info and time. So that's what I also try to talk to other patients about asking for more info and time to help make the changes.
>
> (Participant 4)

Participant 3 shared that they had experienced a lack of clarity regarding the details of their treatment from their health and medical professionals or they felt that they did not explain what was going to happen across their treatment plan and interventions, suggesting that clinicians deliberately use clinical jargon that confused the participant and created a power imbalance between clinician and patient. By keeping health professionals in control, they felt they were deliberately using clinical terminology and not explaining it, making it difficult for patients to acquire skills to slow the progression of the disease, due to gaps in their knowledge:

> They give you some paperwork, about how a fistula works. But they don't sit down to explain it to you, and try and talk to you, in a way that you understand, and in a context that you understand. They are very much switched into their world, and in a world that they operate. In the medical world. Using jargon, and stuff, and some of them forget that we are everyday people, and understand that Anastomosis, or is and the clinical language. So, I feel that there are a lot of gaps to be filled in.
>
> (Participant 3)

Participant 4 reflected on the complexities associated with the disease and how CKD may be linked to other health conditions or comorbidities. They found that not understanding the complexity of the disease and not having enough early advice on health interventions reduced opportunities to improve their health outcomes, by making changes to slow disease progression:

> …I needed info earlier on, when I was heading for dialysis, and where I needed to lose weight and to cut back on your alcohol, and I needed to exercise. Again, at that early stage, the problem is with diabetes, is that you have no real symptoms, and you might feel a little bit lethargic. I missed the chance to change ‘cos I didn’t fully understand.
>
> (Participant 4)

Subtheme 1.4: Power imbalances limited sharing of information

It has been suggested and expressed that there may be concern of power imbalances between health professionals and patients. There were instances where health professionals appeared to be in a hurry or somewhat rushed, which may have created a sense of power as they were focused on other tasks and in control of the time they allocated to patient interactions. Some participants expressed a feeling that they had not received appropriate or adequate information, feeling they had been ignored, or had been overlooked or “hurried along”:

> …lately… I have lost a lot of weight, but to get that information, I’ve had to jump up and down, and really make a scene, to get my doctor to call me back to tell me what’s going on. He saw me the other week and said “ I’m really surprised at how much weight you have lost”, and I felt like saying “ that’s why I have been trying to get a hold of you” but I didn’t., I feel like they have five minutes spare, or what have you, and realistically it’s a really quick, hurried conversation.
>
> (Participant 1)

> I do ask the questions that I want to ask, and they don't always appreciate it, and that they don't like being questioned too much. But I'm one of those people where I need to know, If I don't know something and it's not giving to me properly, my source, then I will find it myself and a source for myself to it appease my questions but, no. I don't get it if I truly, really ask for it even then when I feel like it, they resent, helping us in the capacity that we have asked.
>
> (Participant 3)

> I would say I was pushed to get the fistular in my arm because I had that Vas Cath put in, in my chest, and they obviously pushed for me to get the fistular in my arm, and that happened pretty quickly. So, I could understand why they wanted to do that and it was really to get the Vas Cath out of my chest, as it's prone to infection and stuff, it was scary though, and it was very overwhelming, I also understand that it was needed but it was rushed, it wasn't my decision and they held the power there… well, it's my doctor who has decided.. the whole thing
>
> (Participant 5)

It was expressed by some participants that they had some understanding of the challenges faced by the health system, and that it was under pressure, particularly due to a lack of staff and shortages. They also acknowledged and realised that staff members might not have time to devote to them, or dedicate time to them, depending on staff allocations and time management, such as the doctor or specialist allocated time and patient time ratio, and how these impacts on their experiences within the healthcare system. Some participants also shared feelings of powerless or helpless, because they could not access support and information they needed:

> I can understand, to a certain extent, because I understand that this is a medical issue and I understand, that there is a shortage of nurses, and that there are excess of patients and stuff. But I find that there are times when they can't give me 10 minutes of their time, to answer my questions. You know, so it gets really frustrating.
>
> (Participant 3)

> As soon as you assert yourself, you are seen as abusive, and it's like, well, I don't want to get a bad nurse, you know? Next thing she's, you know, I'm not getting the treatment I need, and they are going to hurt me. It's terrifying and it makes you feel like you're not important, you're not worthy of their time, worthy to talk to, and you have to deal with it.
>
> (Participant 5)

> The one response that I got, was that it was a foreign object, and it was prone to clotting. So, it wasn't anything personally about, me or my body, or if there is anything wrong, with me or my vessels, it was basically, because it was a rubber tube. It's a foreign object to your body. So, it's more likely to clot, and that was the explanation of that I got…. So, they never really explained anything to you about it, until it happens. So, you have no idea what's really going on. Like when there's clotted.
>
> (Participant 4)

In certain situations, participants described the realty of staff in the unit, as it really depends on the context and who is on shift, as the patient wants continuity of care and to form an appropriate relationship to improve their health and well-being, and not power imbalances from different health professionals, as the participant described:

> When it comes to someone I don't know, I usually just keep it to myself and deal with it, or hold on to it, until I know I'll speak to a nurse that I know and talk to when and not be so nervous. So yeah. It depends on the context really, generally, I'm, If I don't know them. I'm very nervous. I'll ask, and I might not talk to them about it, basically because depends on who it is. Yes, so I can be nervous so, and I refer to my nephrologist by first names.
>
> (Participant 3)

In certain situations, patients are not provided with sufficient explanation or informed, or educated, particularly about their fundamental rights. It appears that many Aboriginal and Torres Strait Islander patients are unaware of their rights, are not fully informed, are unaware of treatment options, are not provided with information, education and are unaware of their right to refuse treatments until they have sufficient information (to be able to make an informed choice). When the patient constantly feels the need to agree, or under pressure, as described by participants:

> No, I didn't know that I could refuse. No, I wasn't aware that I could refuse it. I just felt that I had to do it, and I feel that its fear mongering and they make you feel like you have to today this. For us, you know. Or you're going to have mental health issues and die, like that's basically it, there is no compassion.
>
> (Participant 3)

> [health professional] wasn't helpful at all, and I really didn't get any information at all, and when I asked for it (they) become very frustrated, really. I don't feel really very supported at all. I was not getting enough support from (the health professional) and my family as well so it was all rolled it all up in one, and (the health professional) I became this massive resentment to deal with.
>
> (Participant 4)

Sub theme:1.5 Psychological impacts following attendance at treatments

Several participants reported feeling uncertain due to their complex kidney health condition, which was impacting their psychological health and well-being. Where the uncertainty can be based on fear of the unknown and is usually compounded by distress or trauma. They reported feeling unnecessary distress when they did not understand the health professional's information, education, advice, or if their concerns went unanswered/unaddressed.

> I felt that there was enough time to process it, but I wasn't able to process the information (about possible treatments). It was told to me quickly, not in the capacity that I prefer. Because, I was not given the information needed to process it, everything, and I feel like I didn't have the tools to process it.
>
> (Participant 3)

Participants also described feeling worried when healthcare professionals withheld information or treatment or did not discuss or disclose information with the patient, especially when they were not fully informed.

> I'm still learning things, even if the doctors tell me, I'm still learning and asking. I even asked the nurses, “what does this do”, and little things about this and that, but I feel they leave out the important bits, and so I worry, and I still don't understand.
>
> (Participant 5)

> They never really, mentioned anything until I had a question about it, you know. Because I also have a graft. So, I have a graft on my left forearm, and when they put it in, I wasn't really given it any information, of why it was put in, it wasn't until I asked… So, I said to my vascular surgeon, “why was a Graphed installed in my arm?”, he said that my vessels were too small and like I said, “you couldn't do it in another place?”, He said no, we chose that spot because, that's where it was going to go, So then I was like OK, you know, I didn't question it, too much because I don't know it, and I have to roll with it, and then after like a month and a half it clotted.
>
> (Participant 3)

It was reported by several participants that they had experienced a sense of psychological distress and worry due to a decision that was made for them, without the opportunity for explanation or discussion. There was also a feeling of fear around not knowing and of being ignored when questions were asked. While the participants experienced additional stress and worry, there was also an increased feeling of trauma as they often worried about the consequences of the decisions, including the possibility of possibility additional pressure put on their family members, especially when they were moved away from family and community:

> I was in [my regular treatment location] and I was getting ready for dialysis, they tried to cannulate me, and they could not advance the needle. After six hours of trying a decision was made for me to go to [an urban hospital]. It was a flight on a Saturday night, then we had to drive through [a city], it was horrible, and an ambulance driving two kilometres an hour. I was so stressed out, then I ended up being away from my son for six days. They took me down there with no explanation, and there's no surgeons on a weekend. So, I had to wait till Monday afternoon, to go to Radiology. … they never explained any of it

> to me. I was scared and they just said: this is just what's going to happen- they said it over and over... They didn't say why, or explain any of this situation to me, nothing, and you're already an emotional wreck, worried for my son and everything. But nothing was explained to me, I was so upset and in trauma.
>
> (Participant 3)

> [clinical decisions] are not something that I have been able to fully take on board. I am left feeling stupid and worried because I just don’t know. Because I don't have all the information I want, and I don't think I have had time to fully absorb it. Because I still have those unanswered questions, and it's a thread that's not going to end until I can get those answers, to the questions. And I worry about how my family are going to understand it all.
>
> (Participant 4)

The importance of making and arriving at a decision is important. This is where patients may need more time to ask questions and understand what is going to happen. The patient must therefore rely not only on the advice, but also on the way in which it is communicated to understand, then be able to apply the information, ask or clarify any questions, and receive appropriate answers or further explanation.

In how clinical decisions are made around treatment options and the patient's health status, but communication may be limited, and information or advice may be withheld from the patient as described by the participant:

> What decision to make in regards dialysis, I think, what I think at the end of the day, the nephrologist done the medical, and the medical staff have the final say on the treatment that I have received. It was purely based on my health at that time. It was decided that haemodialysis would be the best option for me, and I wasn't working at the time. No mention about how my family could support all that, and that really worried me... I don't know, I think that made me feel stupid to be worried about so many things and so many people. I just was sick and wanted to get better. Too many extra worries.
>
> (Participant 3)

Theme 2: Advocacy for self and others

Participants reported needing to advocate for themselves and for others. Expressing the importance to be empowered to self-manage their own health outcomes, as this includes autonomy and self-efficacy in many situations. Participants reported having to advocate for themselves and understand the healthcare system in how it works and where to go to when problems arise, or for urgent health matters. This was made difficult for patients if they didn't speak English as a first language where many Aboriginal and Torres Strait Islander languages is their first language,

It is important to note that many Aboriginal and Torres Strait Islander people are overwhelmed and reluctant to get additional help to improve their own health outcomes, leading to a decline in their health.

Subtheme 2.1: Seeking own resources and research to supplement knowledge

Several participations felt that they must do their own research themselves to gain an understanding of their own health condition:

> You have really only got to do your own research to keep yourself on the straight and on the right track.
>
> (Participant 1)

> I've been struggling a lot with my eating as well as my liquid intake. So, I'd look on Google to things to what I can and what I cannot eat, even though I was given what I can have, I've lost that form, and I've been relying on Google and stuff like that.
>
> (Participant 5)

> Ask Google; the Facebook, Australian Dialysis site, which is very, very handy, very, very handy.
>
> (Participant 1)

> No, I found it was just a lot easier to randomly ask people, if it was other patients in a clinic, I asked them how they are going, what their opinion based on …. and then I would make my own choices.
>
> (Participant 2)

> I ask questions, whether they like it or not? So, I do ask the questions that I want to ask, and they don't always appreciate it, and that they don't like being questioned too much. But I'm one of those people where I need to know, If I don't know something and it's not given to me properly, then I will find it myself, and a source for myself.
>
> (Participant 3)

Some participants felt more comfortable conducting their own health research or felt more comfortable asking questions of other patients before requesting additional information from their healthcare professionals. Where Health professionals don't like to be confronted or challenged:

> I would rather go out and do my research, and part of that research is talking to people and getting their thoughts, asking “what happened to you here?”, “did this work or didn’t it work, did that work?”, so that I can then do what I need to do. I will take all that back to the nephrologist. But it is really hard to get a hold of your doctor, your specialist at any given time, what they will want you to do is to just tell the nursing staff and the nursing staff just go, “um, um, yeah, that’s great to know, thanks (participant name)”, and you will never hear anything else about it.
>
> (Participant 1)

Participant 1 expressed the need to do research for themselves, because information and education was not given freely and so one had to advocate for oneself (self-advocacy):

> I'm the one doing the research into it, and it's not really given to me freely.
>
> (Participant 1)

Similarly, participant 2 spoke about the importance of self-advocacy, self-care, self-management and self-efficacy, so that their health did not deteriorate rapidly. They expressed that this was up to the patient to do, otherwise nothing would happen in a timely way:

> You really have got to be proactive and advocate for yourself and if you don't do that then you are always going to be sitting on the back burner until someone goes "I forgot about [name of participant], how are you going?", so you have really got to push it, otherwise if you don't push it nothing will happen for you.
>
> (Participant 2)

Subtheme 2.2: Yearning for culturally appropriate care

The importance of community, cultural connections, and to be included was seen as a vital part of the CKD treatment and care process. However, participants Yearned for being respected by their healthcare professionals, they Yearned for a connection with the clinicians and to feel comfortable in communicating their wishes and concerns. However, some participants indicated they can only get this when they approach other patients:

> So, they come to me rather than the doctors and it's because they feel comfortable talking to another Aboriginal person.
>
> (Participant 4)

Language was one of the important issues raised for Aboriginal and Torres Strait Islander people, as there are many languages. It was seen as crucial to the health and wellbeing of patients, as well as increasing the patient participation and engagement in health knowledge and decision-making. Some participants suggested that use of culturally appropriate Aboriginal and Torres Strait Islander languages happened mostly between patients, and not from health professionals, medical staff and surgeons or from other resources given to the participant.

> I can always use it [a resource] in language with another patient. So, it's like comfortable with language. I know sometimes when I feel like English is not comfortable, it's sometimes about getting information the right way across. Isn't it just talking with other patients and going from English to their main Aboriginal language for [other patient’s name], first language is a community language, then to English, which is a seventh language for her! So sometimes it's actually just getting it from one language to another language. And sometimes we do that between ourselves.
>
> (Participant 2)

> Some people, Liaison Officers are always involved in patient care, but I said “no, they're not”. I've seen them come in do their obs (vital signs, observations) and off they go, and I said, “well, why aren't they in here, when I am are talking to the Diabetic Educator, and they should be offered to patients”. Again, I talked to other patients, “are you alright to see the doctor?” They said “no, I want you, to come in with me”.
>
> (Participant 3)

Aboriginal liaison officers or Aboriginal health workers were seen by participants as ignoring them and creating divides, where it is meant to be culturally engaged services and support for patients, but it is not. Yarning for improving health and wellbeing through shared knowledge and experiences, was considered important and the need to support Aboriginal patients was high. However, Aboriginal health workers or Aboriginal liaison officers created divisions and appeared not to care but was only for their jobs. It was mentioned by some that Aboriginal workers or liaison officers also support social connections needs, recognizing the importance of shared experience that came through one another, through culture and connectivity. Yarning, revealed that participants saw the Aboriginal Health workers as being caught up in the bigger non-Indigenous systems:

> For me, this is a role for the Aboriginal Liaison officer, meaning they are supposed to be supporting patients, you know. I found him [a doctor] a bit abrupt, you know. So, then I spoke to one of the Aboriginal Liaison officers and I was surprised by her reaction. She came back, defending the Doctor, and I thought, hold on, just because you work for [a health service] you are not here to defend the doctor, you are here to support the Indigenous patients. Luckily, I've ended up with a good doctor after that, who I've had for basically the five years.
>
> (Participant 3)

The importance of culture and community and the relationship between health and kin, and family, was positioned against the reality of the current health and medical system that disconnected and isolated patients and families. Some participants expressed a desire for health care to be delivered on Country, and their wishes were not respected. Other participants recognized a deterioration in their health when they moved away from their Country, their communities and were not connected with culture and language. Participants described that they wanted to return home to each other and that they wanted to die on Country with their family and loved ones, if they were close to death:

> So, that is one of the things that I see especially the mob from the (regional area), they come down and they are removed from their communities, their culture, their Country, you know. And then I've seen patients that go downhill so quick, and I've talked to one patient and every time I see her, she says “I want to go home, I want to go home”. Unfortunately, she did go home, not the way she wanted, you know, she went in a box. That's what happens, and they don’t want to die down here, they want to die on Country.
>
> (Participant 4)

> I want to have my care right here, where I can stay connected to mob and family. I want to stay on Country, but they have me travelling for specialist. I am so worried I will stay off Country one day ‘cos I am too sick to come back.
>
> (Participant 3)

Subtheme 2.3: Develop relationships through informal Yarning sessions and shared experiences

Participants valued connecting and Yarning with other patients about health matters, and staying strongly connected to culture and Country:

> It's about my health. You think your health is the most important thing when it's not, you find that the most important thing is the doctors schedule, and it turns out that you are better off to talk to other patients. I find talking to other patients that is really good, because a lot of these people have gone through the same thing as you will, so it is important to have a Yarn with other patients about their experiences. Therefore, having a good Yarn to other patients is important, as it can be hard to know what the doctors or specialists are really on about as they don't have the time and other patients have gone through the same or similar thing and the importance of self-advocacy and being proactive.
>
> (Participant 1)

> Look for me, don't take me the wrong way, I'm just an educated Aboriginal and Torres Strait Islander person. So, I feel confident and comfortable and asking questions if I don't find stuff, or if the information is not readily available. I think for other patients, where English is their second language, there is probably not a lot of cultural information to make it a bit easier…people with poor literacy skills and even low confidence, so they tend to use me a bit here, which I don't mind. This service has done a video, which is meant to be playing, I'm talking about my journey, and I go around talking to the dialysis unit and talk to the patients around about a possibility of Staying connected to stay as well as we can be.
>
> (Participant 4)

Chapter summary

In summary, several main themes emerged from participants' experiences that connect them to improving their own health outcomes and making decisions about their own health. However, it is important that each participant has different experiences, perceptions and insights, therefore Yarning allows additional engagement, participation and collaboration where Aboriginal and Torres Strait Islander patients can maintain connections and stay strong. Gaining support from others such as through Yarning improves health outcomes. My research focused on health information, education, advice, literature, literacy, and engagement and participation with their kidney health.

Many participants know or acknowledge that they did not receive or were denied access to information, education, advice, or that the information or education was inadequate or inappropriate. This is a difficult area because they knew that they had been denied knowledge and literacy to improve their health, and to some extent understood that this violated the right to be fully informed, creating barriers. As it also infringed on the right to be fully informed participants' autonomy including decision-making and planning was not respected. My research allowed participants to Yarn about their experiences and gives them a voice to be heard. My research has touched on medico-legal issues, policy considerations and fundament human rights. When some participants knew and others did not know about being fully informed, understanding the procedures, and consent. It is important to note that each participant has different experiences, but they share one thing in common, that the information, education and advice available is inadequate or does not meet their health needs and it is not personalised creating uncertainty. Therefore, the participants had to conduct their own research, to better understand their own health.

My research found that most participants were proactive and sought their own research to gain knowledge, awareness and develop skills. In assisting them to make informed decisions, plan, take care of themselves and self-manage throughout their kidney journey and to navigate the health system.

Chapter 6: Discussion

6.1 Reflecting back

My research explored the question “What is the lived experience and value of renal health literature, information and resources in the lives of a group of Aboriginal and Torres Strait Islander with kidney disease (renal patients)?” That question evolved from the personal experiences I had as I cared for my Mum throughout her journey as an Aboriginal renal patient. It also evolved from my academic curiosity to develop better understanding of what other Aboriginal renal patients were experiencing, in terms of the health literature, information and resources they encountered that helped them to make informed decisions about their care. In Chapter One I presented my study rationale, explicitly noting that the inspiration of my research came from my mother who passed away from renal failure. I walked with my mother through her journey, and noticing many of her healthcare professionals tried not to keep her fully informed; and her questions were mostly met with silence. My positionality as an Aboriginal research student was presented in this chapter as I wove together my personal and academic interests in this research. I also provided a summary of chapters.

In Chapter Two I described the important Aboriginal and Torres Strait Islander health and history context, presenting historical and current health policies and practice developments that have impacted on Aboriginal and Torres Strait Islander people and their health, within the context of CKD.

Chapter Three presented a synthesis of literature related to Aboriginal and Torres Strait Islander CKD, treatment experiences and CKD related information and resources. In Chapter Four I described my research methodology and methods, including some of the theories that informed my chosen methodology. Importantly, I linked back to my own positioning as an Aboriginal researcher, describing how I have been guided by the Western ethical frameworks and governance requirements of this MPhil research and by cultural ethics and values.

Chapter Five presented findings of my research, derived from the analysis of the data, that I generated from the participant interviews, and present two main themes and sub-themes:

Theme 1: Challenges when trying to access health education

Subthemes:

1.1 Withholding information regarding treatment options

1.2 Limited resources provided

1.3 Missed opportunities to delay disease progression

1.4 Power imbalances limiting sharing of information

1.5 Psychological impact following attendance.

Theme 2: Advocacy for self and others

Subthemes:

2.1 Seeking own resources to supplement knowledge

2.2 Yearning for culturally appropriate care

2.3 Developing relationships through informal yarning of shared experiences.

Participants identified challenges they faced when attempting to engage with CKD health literature and resources, describing missed opportunities throughout their health journeys that might have been improved with a more consistent and bespoke approach to their care. Importantly participants also shared data describing the importance of self-advocacy and the importance of advocating for others. They provided examples of how they sought their own CKD resources, yearned for a more culturally aligned model of care, and highlighted the vital role of relationship building through sharing CKD journey experiences.

Data from Theme Two “Advocacy for self and others” surprised me, especially as my questions focused mostly on existing examples of resources and information shared with participants by their treating health professionals. The participants wanted to highlight to me that, above or in addition to existing resources, it was advocacy for self and others that really made a difference. The findings in Chapter Four present an opportunity to make changes to how Aboriginal and Torres Strait Islander people living with CKD are provided with support, resources, health information, and treatment options. These opportunities could have an important impact on patient health and wellbeing throughout their CKD journey and could ultimately uphold the commitments to centering Aboriginal and Torres Strait Islander voices in health care that is foundational to any effort that is made aligning to the Closing the Gap policy framework (Commonwealth of Australia, 2024; Baldwin et al., 2025; Bond & Singh, 2020; Schultz, 2020b).

The themes and subthemes in this chapter ,my discussion chapter (Chapter Five), draw on the data detailing experiences of Aboriginal and Torres Strait Islander participants as they reflected on their health journey, and on the support and resources that impacted their kidney health outcomes, their quality of health and quality of life, within the Western health system that centers on Western biomedical practices (Gatwiri et al., 2021). An overarching dominant finding was the lack of agency and voice that all participants experienced. This deficit took different forms across the participant cohort, but collectively the group describes a common experience of feeling powerless, voiceless, or feeling omitted from their own health decision planning. While other themes and subthemes expressed other concerns or challenges, this overarching, shared experience aligns with the literature, Chapters Two and Three, on historic and current experiences of exclusion in health services (Gorham et al., 2022; Gwynne et al., 2018), policies (Jardine et al., 2017; Langham et al., 2022; Paterson et al., 2023) and practices (Pascoe et al., 2025; Rissel et al., 2022; Rix et al., 2015; Sherwood, 2013; Sinka et al., 2021).

Participants frequently expressed concern as they reflected on feeling unsure in approaching and asking health professionals about their health, or about their treatment options. They felt the same caution when they were wanting to ask for more information and resources to improve their understanding of options. This overarching sense of insecurity linked to the frequent power imbalances described by participants as they “just were handed bits if paper” without explanation or time for questions, or they felt “rushed into a quick appointment” with clinicians who appeared “too busy to care”. Feeling voiceless left the participants vulnerable, often accepting treatment options that were handed to them rather than collaboratively formed, mostly needing to find their own CKD resources and information due to the lack of specific or personalised approaches. This overwhelming common finding provides a cohort specific example of why the original Closing the Gap policy framework underwent a major revision. The first policy framework did not center Aboriginal and Torres Strait Islander people and voices, did not include Aboriginal and Torres Strait Islander leadership, and did not engage with Aboriginal and Torres Strait Islander ways of knowing, being and doing. As a result, Australia's first national policy attempt to make significant changes for Aboriginal and Torres Strait Islander people was experiencing poor performance and showing signs of failure (Bond & Singh, 2020; Parter et al., 2019).

After intensive review the national policy was refreshed, this time ensuring more collaboration, inclusion, leadership and voice of Aboriginal and Torres Strait Islander Australians (Australia, 2024; Baldwin et al., 2025; Schultz, 2020b). These changes spoke about the recognition of how important it is to have a 'nothing about us without us' approach. The findings of this research still reflect ways of working with Aboriginal and Torres Strait Islander people living with CKD that align with the first Closing the Gap policy framework, showing that policy change takes time and systems potentially take even longer to implement policy change. Participant experiences showed little, if any, attempt to adopt inclusivity, cultural engagement, shared decision making or patient centred ways of supporting Aboriginal and Torres Strait Islander people living with CKD. This is a missed opportunity for Aboriginal and Torres Strait Islander people and a missed opportunity for the CKD health system to vastly improve the ways of working to better meet the needs of Aboriginal and Torres Strait Islander people living with CKD(Baldwin et al., 2025; Bond & Singh, 2020; Parter et al., 2019). The Aboriginal and Torres Strait Islander participants in this research described experiences that create space for this learning and change to happen; their data inspires opportunity for change.

6.2 Opportunity 1: change access to health information and ways of providing clinical support for Aboriginal and Torres Strait Islander people living with CKD

This opportunity arises from data analysed under Theme 1: Challenges when trying to access health education and information. It is important to beware that a decline in kidney health can have a detrimental impact on an individual's physical wellbeing, their overall quality of life, and their general state of health. Therefore, it would be beneficial for patients to possess adequate health literacy and have access to information that is pertinent to their condition. This should include details of the various symptoms associated with kidney disease, such as itchy skin, weakness, burning sensations and the impact of dietary and nutritional advice on the condition. Additionally, it may be beneficial for patients to be aware of the importance of maintaining a healthy body weight, managing general tiredness, weakness and fatigue, and understanding the potential side effects of medications, as medications can have various symptoms that impact on a person's kidney health and their health outcomes (Alkhatib et al., 2023; Evangelidis et al., 2019; Fadem et al., 2023; Ikizler et al., 2020; Neale et al., 2023) . It is vital to convey information and literacy pertaining to kidney health must be conveyed in a straightforward manner. Participants describe experiences with the types of information, education, and advice provided to them by healthcare professionals to improve their kidney health and awareness.

However, participants in this study described the complex nature of their kidney disease and the treatment options available to them and expressed a lack of availability of adequate resources and support from their healthcare professionals (who were often locked into very short consultations and always busy).

Participants experienced pressure when trying to access health resources and information, with their health professionals often not spending time (for various reasons), resulting in the participants not having enough access to clinician provided knowledge and resources that could have increased participant awareness, understanding of their status of health, and boosted their own capacity to improve their health condition and slow down the disease progression (Bateman et al., 2023). This also includes time allocation, including appointments with healthcare professionals, due to the system's design (Baum, 2007; Fisher et al., 2019; Marmot, 2005; Pearson et al., 2020) . There is an opportunity to review the pace of patient/health professional interaction, even within a time poor health system.

Participants raised concerns about health information, education and resources not being personalized, when provided to them from health professionals. They stated that one of the main problems was the lack of access to reliable and good quality information, education, and advice that was customised for Aboriginal and Torres Strait Islander patients. Tunnicliffe et al. (2024) discuss clinical practice guidelines that advocate for improved resources and a more time sensitive way of working with Aboriginal and Torres Strait Islander people living with CKD.

Several participants described how they felt their healthcare professionals had withheld information, health education publications, or inadequate information about treatment options. Although some were comfortable asking questions to obtain information from their healthcare professionals, they felt that asking questions resulted in more of a confrontation, rather than in supportive or helpful knowledge exchange.

One participant described having to “cause a big scene” because information and education was not provided freely, in a timely manner, and felt it was inadequate and did not meet the participant requirements or needs. Where the participants raised the issues about having autonomy and self-advocate: in obtaining their own information and not to always relying on health professions to provide information and education.

Self-advocacy was key to obtaining information about treatment options. As one participant explained, one must be comfortable enough “to cause a big scene,” so the clinic would then ask the doctor to call you. Having considered access to clinical advice and support should not require patient stress but “making a scene” was described as the best way to get noticed in a way that would result in an appointment within a reasonable timeframe (for this participant the timeframe for waiting for this advice was still 3 months). Another participant described how they are careful not to make a scene when they ask for additional information to support their decision making and healthcare, because making a scene positions you as complaining, and with that positioning often comes knee-jerk reactions that hinder access to appointments and clinical care (Health & Welfare, 2020a, 2020b, 2023a; Paterson et al., 2023)

When some participants knew that they were not receiving the care and treatment that they needed or required, and they urgently sought health information and support, they faced a necessity to “cause a scene”, considered an essential part of the participant’s treatment and the process that helped to facilitate access to health resources and support

Participants talked about having options, choices, and information seemingly withheld by their health professionals; this made the participants frustrated and not in control over their health. Several participants felt that there were barriers to their care and treatment options. Health professionals did not help them make decisions about treatment options or planning and the participants put this down to disrespect and biases to their care (Meijers et al., 2023) . Several participants felt uninformed or believed that they were misinformed or believed that healthcare professionals were knowingly making treatment decisions for them and not with them, (Dimopoulos-Bick et al., 2023; Fildes et al., 2022). As one participant expressed: “…I was just told, and I just pretty much went along, I was told what was needed for me” (Participant 5). Another described not having enough information to fully understand (after asking for it), and described just doing what they were told: “… I just went along…because I've never heard of peritoneal? What is that exactly? (Participant 4).

One participant describes what happened as a new patient trying to obtain timely health information and education provided by healthcare professionals: “From the beginning stages, nothing; They do give you bits, of paper... the little bits of paper because you have never done it before, it’s a little bit confusing so, you are really just taking the advice of the doctors” (Participant 1). However, participants all wanted to feel they were fully informed, and they feel they need to be fully informed, to know about procedures and symptoms, rather than not having them well explained. (Al-Wathinani et al., 2023; Gotlieb et al., 2022; Pitt et al., 2020). Some participants continued on with their care even if they had asked questions and had no responses.

They remained disempowered and confused, but carried on with their treatment, in the face of not fully understanding key issues. This was particularly evident when participants faced issues related to transplantation:

> …I think that there is a generalization, because you’re Aboriginal or Torres Strait Islander, family members can't donate, and I said, ‘hold on, my sister is 62 (years old) and she's not diabetic, and no heart condition, and you're telling me you won't even look at her?” No, because she's Aboriginal and there's a risk that she has the natural tendency to diabetes, because of hereditary. I just thought that was a generalization, and that it is a real stereotype. You need to assess every patient as an individual, and that was one sort of thing I struggled with. (Participant 5)

There is an opportunity for the clinicians in the system to review how questions are asked and answered. Being denied information becomes devastating and frustrating as there is an underling stream where the doctor and specialist know ‘what is best’ but they don’t always have the time to explain this information to participants, It also enables an environment of power imbalance that takes away all possibility of agency over one’s own health (Lakhan et al., 2022).

Participants described insufficient, inappropriate and inadequate education and practices, which adversely affect their autonomy. Participants indicated that healthcare professionals deliberately choose to limit the information they provide, or simply withhold it, leading to a lack of trust between participants and deteriorating the existing relationship with the health professionals and the participants yarned that could have been prevented (Tunnicliffe et al., 2024):

> I'm never being given any information unless I ask for it, and then…the information that they have been given to me, or the lack of information is not great, so, generally I will... Look it up myself. (Participant 3)

Participants yarned about the information or advice that was provided to them from health professionals as being “not enough”, but also yarned that it was not personalized, or it did not meet their needs. This approach goes against holistic care and ignores the important value Aboriginal and Torres Strait Islander patients place on building relationships in clinical care (Geia et al., 2013; Murrup-Stewart et al., 2021) .

In addition, several participants reported receiving little or no support, in some situations, no communication with the healthcare professional, regarding information, education and information, and that they felt that there were barriers in understanding treatment options (Chaturvedi et al., 2024; Garcia, 2024).

Address missed opportunities to slow the disease progression

In this study participants expressed that they were unable to improve their own awareness of the disease process because they felt there was no support available and that there were barriers in navigating the health system. These barriers often led to missed opportunities to make choices that could have slowed the trajectory of the disease (Kerr et al., 2024).

Participants also noticed minimal (if any) Aboriginal or Torres Strait Islander health professionals in their circle of health service, that share the same culture and language. This was identified as a problem because of the importance of cultural engagement and support and relationality in Aboriginal and Torres Strait Islander health service provision (Tong et al., 2020).

Improving relationality and communication styles in CKD service provision is an opportunity to address this issue. Participants yarned about that they felt when health professionals did not communicate with them, some feeling that their health professionals just did not like to communicate with patients, and other participants suggesting some health professionals were unsure of how to communicate with Aboriginal and Torres Strait Islander patients (Kerr et al., 2024):

> So, you know, yeah if we had someone to help us better understand we might make choices to slow things down, in a good way. (Participant 4)

Participants Yarned that they are finding out information for themselves in difficult situations (poor health and unwell) because they feel that they are not informed, they find that specialist advice and health professionals don’t discuss some of the complications and complexities of the disease and disease process. Some participants suggested this was also linked to communication issues between health professionals and patients. They suggested that they became unsure of things, and made wrong decisions because there was no, or little guidance:(Lin et al., 2023; Lin et al., 2016; MacAskill et al., 2022) .

This highlights the need for appropriate intervention, information, advice, education and resources communicated in ways that best support the participant in a timely way (Langham et al., 2022; MacAskill et al., 2022).

Building relationships in clinical care that engage timely communication was considered really important and also lacking in the care experienced by many participants in this study. An opportunity to change that faces the sector. For one participant a lack of in-depth information meant they didn't act earlier, stating that if they had more time and more information they would have made different choices earlier in their journey of health.

> …But I needed more info to understand why I needed to change. I needed more info and time. So that's what I also try to talk to other patients about asking for more info and time to help make the changes. (Participant 4)

Participants discussed that health, and medical professionals did not explain or feel that they don't have time to explain, or to go in depth or discuss what was going to happen. Often the health professionals appeared to be in a hurry, giving a sense of that they are needed and have limited time for the patients, not explaining the situation and what the patients need or should be doing to improve their health, or they may explain health matters in simple way but does not elaborate on how to improve their health (Nash & Arora, 2021). Additionally, health professionals that deliberately used clinical jargon or medical terminology were considered to do it with the intention to confuse participants (Gotlieb et al., 2022; Pitt et al., 2020).

These types of experiences highlight the inequalities within the healthcare system, where knowledge is needed to improve the health and wellbeing of patients from a holistic perspective. However, the risks and complications were not always explained to the participants in this study:

> … So, the safest bet was to do this hemodialysis, ya, and knowing that was just by accident, so yeah, no one tells you really, what's going to

> happen, what’s expected Blah, Blah, Blah, or how it does it, nothing, nothing, nothing, nothing really. (Participant 1)

Missing opportunity to take time, communicate well and ensure information is well understood seems to be foundational in a model of care (Tunnicliffe et al., 2024), but still absent across participant experiences in this research.

Opportunity 2: address the power imbalance in clinical care through relationship building

Participants expressed concern over the power imbalance between health professionals and patients, suggesting this is built on experiences of withholding skills and knowledge. Participants noticed that health professionals hold power and responsibilities, and they feel that there was a focus on other things rather than the patient's health and wellbeing. Participants expressed the sense of being a bother, of taking too much time up from the health professionals schedule, feeling they have been ignored, or had been “hurried along” and that they felt that there was not enough time for them. This increased the sense of powerlessness in participants.

Time pressure within a system (Dune et al., 2021; Muscat et al., 2018; Muscat et al., 2023) had filtered into the experiences of health service across the cohort in this study. Participants described how the health system was under pressure, particularly due to a lack of staff (Mistry, 2024; Rissel et al., 2022). Time constraints were very evident to the participants, but also had the effect of imbalance of power- the system (and time pressures) held power, and the patients were left to experience this. The system constraints included patient appointment time and availability for appointments and staff not having time to devote to patients. Participants recognized that they were powerless or helpless, because they could not access support and information, but the pace and lack of time was mostly experienced by participants as more important than the actual delivery of service (Calleja et al., 2023).

> … I understand, that there is a shortage of nurses, and that there are an excess of patients and staff. But I find that there are times when they can’t give me 10 minutes of their time to answer my questions. You know, it gets really frustrating. (Participant 3)

The opportunity to better engage patient centred models of care is well supported by current guidelines and Aboriginal and Torres Strait Islander policy frameworks (Commonwealth of Australia, 2024; Tunnicliffe et al., 2024). However, the lived experience of lack of time presents as power imbalance, and of lower valuing of patient experience:

> …It's terrifying and it makes you feel like you're not important, you're not worthy of their time, worth talking to, and you have to deal with it. (Participant 5)

Improving communication and time allocated to Aboriginal and Torres Strait Islander patients has potential to reduce the sense of power imbalance and avoid making the participants feel that their health needs are their problem, and the time demands of working as a health professional are more important (Burnier & Damianaki, 2023; Stevens et al., 2024).

Opportunity to build better therapeutic/clinical relationships

Participants described how, despite knowing personalised care is important in CKD, they seemed to obtain similar or the same information and advice but require personalized information. Participants reflected on the importance of feeling like relationships were built into their model of care, suggesting that there need to be relationships with trust and appropriate time for the participant. Importantly, they described issues of having lack of continuity of care that often came with forming appropriate relationships (Bateman et al., 2023).

> … If I don't know them. I'm very nervous. I'll ask, but I might not talk to them about it, basically because it depends on who it is. Yes, so I can be nervous, so, and I refer to my nephrologist by first names, [which is not taken well]. (Participant 3)

Participants expressed the vulnerability that comes with having decision made ‘about them without them’ (Dimopoulos-Bick et al., 2023; Meijers et al., 2023). They reflected on the focus as being making the patient compliant (Kennedy et al., 2022)and always in agreement with health professions, rather than taking time to build appropriate connections and relationships (McClellan et al., 2004; Willows et al., 2023) . A participant explained that adherence to medication is vital, but the emphasis is more about taking the medication rather than explaining what it does, the mechanism or risks associated (Calleja et al., 2023): “They just wanna give us medications but not much explaining” (Participant 2).

A focus on making a participant compliant, rather than making sure a participant has full information, and connection with their treating professionals contributed to a perceived power imbalance (Gotlieb et al., 2022; Pitt et al., 2020) between health professionals and the participants. Taking time to build engaging clinical relationships presents as a major opportunity for the CKD health professionals.

Some of the challenges of access to resources and services present additional psychological burden to a CKD patient, as found in data from participants in this study. Several participants reported feeling uncertain about their future, due to their complex kidney health condition and a lack of ability to access appropriate advice and timely conversations; this impacted their psychological health and well-being. The participants reported feeling unnecessary distress when they did not understand the health professional's information, education, advice, or if their concerns went unanswered/unaddressed as enhanced by a participant's experience:

> … I wasn't able to process the information (about possible treatments). It was told to me quickly, not in the capacity that I prefer. (Participant 3)

Participants were aware of the added psychological distress and worry resulting from when decisions were made for them, without explanation or discussion (Dimopoulos-Bick et al., 2023; Meijers et al., 2023). Current guidelines (Tunnicliffe et al., 2024) and leading work in shared decision making (Dimopoulos-Bick et al., 2023) highlight the importance of patient involvement in decision making. This highlights where patients are not being involved in the process, and where it puts additional pressure put on family members, and on patients, especially when they moved away from family, community and Country for treatment:

> I was in [my regular treatment location] and I was getting ready for dialysis; they tried to cannulate me, and they could not advance the needle. After six hours of trying, a decision was made for me to go to [an urban hospital]. It was a flight on a Saturday night, then we had to drive through [a city]. It was horrible, and an ambulance driving two kilometers an hour. I was so stressed out, then I ended up being away from my son for six days. They took me down there with no explanation, and there's no surgeons on the weekend. So, I had to wait till Monday afternoon, to go to Radiology. … They never explained any of it to me. I was scared and they just said: this is just what's going to happen- they said it over and over... They didn't say why, or explain any of this situation to me, nothing, and you're already an emotional wreck, worried about my son and everything. But nothing was explained to me, I was so upset and traumatized. (Participant 3)

While the experience of Participant 3 is unique to them, it does provide a solid case study about not providing enough communication and information, of making decisions without patient input, and about the burden of fear these elements place upon a sick, frightened patient. While guidelines and current research (Muscat et al., 2018; Muscat et al., 2021; Muscat et al., 2023; Poirier et al., 2024; Recabarren, Dominello, et al., 2024; Scholes-Robertson et al., 2022; Tong et al., 2020; Tunnicliffe et al., 2024) , there remain examples of patients experiencing care that adds to their psychological burden, and to their worry about how their family will also cope: “I worry about how my family is going to understand it all” (Participant 4).

Strengthening shared decision making

Current work in shared decision making in Aboriginal and Torres Strait Islander health settings provides a solid foundation to better embed shared decision making into CKD models of care(Dimopoulos-Bick et al., 2023; Dimopoulos-Bick et al., 2024). Participants strongly supported the importance of making and reaching a decision as a process that involved them and their family’s involvement. Participants suggested that being involved in the clinical decision-making process and in exploring different treatment options positively impacted their health and wellbeing and gave them a sense of agency and strength.

6.3 Opportunity 3: engage with patient advocacy for culturally engaged care (people know what would work for them)

Participants in this study highlighted the role of advocacy for self and others in their CKD journeys. Previously described gaps/deficits in service provision supported participants to engage in advocacy as they attempted to gather appropriate information, ensure enough time was spent with treating clinicians, and develop a real sense of agency within their own health decision making. Advocating for change, or for having things done differently, was an extremely important part of all participant journeys in this research. Participants felt that they had to seek and conduct their own research to gain a better understanding of their health condition and disease process and to have awareness and a better understanding. Experiences of denial of resources or information led participants to feel disempowered in their own health processes; advocating for different ways of working became part of each participant's journey (Bateman et al., 2023) . Self-advocacy was described as essential to addressing any power imbalances (Lin et al., 2023; Lin et al., 2016; Liu et al., 2020; Poirier et al., 2024) or any sense of exclusionary decision making, but it was not always easy to achieve, especially when participants were already very unwell.

Advocating for appropriate, culturally engaged resources was important for participants in this study and connects to current best practice guidelines (Tunnicliffe et al., 2024). Improving resources included improving accessibility and availability of different resources, having resources in their community languages, and having resources that engage with cultural connections (Zupan et al., 2021).

There are more than 325 Aboriginal and Torres Strait Islander languages but there seems to be no or little medical information, education in community languages that are used by some CKD patients (Langton, 2011). Having resources developed in culturally informed ways, to meet the patient needs, is a basic fundamental right. While there is a recognised gap in Aboriginal and Torres Strait Islander health professionals (Kerr et al., 2024; Sinka et al., 2021) in CKD there remains an opportunity (identified in participant data in this study) to advocate for engaging other Aboriginal and Torres Strait Islander people living with CKD (or their families) to provide health translation/cultural translation support – especially until the workforce grows to meet the service need: “I talked to other patients, “are you alright to see the doctor?” They said “no, I want you, to come in with me” (Participant 3).

Until the CKD Indigenous workforce grows, one strategy proposed in this research, is to engage patient co-advocates, “so they tend to use me a bit here, which I don't mind” (Participant 4). The importance of community, cultural connections, and to be included was seen as a vital part of the CKD treatment and care process. However, participants yearned to be respected by their healthcare professionals, they yearned for a connection with the clinicians and to feel comfortable in communicating their wishes and concerns. However, some participants indicated they can only get this when they approach other patients: “So, they come to me rather than the doctors and it’s because they feel comfortable talking to another Aboriginal person” (Participant 4).

Appropriate language usage in models of care was one of the important issues raised by participants. It was seen as crucial to the health and well-being of patients and to increasing patient participation and engagement in health knowledge, decision-making and care needs. Some participants suggested that use of Aboriginal and Torres Strait Islander languages happened mostly between patients, and not from health professionals, medical staff and surgeons or from resources given to the participant (Clemens et al., 2021; Tunnicliffe et al., 2024).

Language was one of the important issues raised for Aboriginal and Torres Strait Islander people, as there are many languages. It was seen as crucial to the health and wellbeing of patients, as well as increasing the patient participation and engagement in health knowledge and decision-making. Some participants suggested that use of culturally appropriate Aboriginal and Torres Strait Islander languages happened mostly between patients, and not from health professionals, medical staff and surgeons or from other resources given to the participant (Clemens et al., 2021; Tunnicliffe et al., 2024).

Participants have raised the importance of culture and the connection to community and the relationship between health and kin, and family, was positioned against the reality of the current health and medical system that disconnected and isolated patients and families. Some participants expressed a desire for health care to be delivered on Country, and their wishes were not respected. Other participants recognized a deterioration in their health when they moved away from their Country, their communities and were not connected with culture and language. Participants described that they wanted to return home to each other and that they wanted to die on Country with their family and loved ones, if they were close to death (Jones et al., 2024):

> So, that is one of the things that I see, especially the mob from the (regional area), they come down and they are removed from their communities, their culture, their Country, you know. And then I've seen patients that go downhill so quickly, and I've talked to one patient and every time I see her, she says “I want to go home, I want to go home”. Unfortunately, she did go home, not the way she wanted, you know, she went in a box. That's what happens, and they don’t want to die down here, they want to die on Country. (Participant 4)

Participants have expressed that they want choices with their care and treatment and where they want their care and treatment to be within their community and on their Country, to have family around them and not to travel for treatment, but in many situations the patients are not heard, they are ignored and it's too late, Family is important for support, and connection to Country, including having care and treatment on Country and in their community, explained:

> I want to have my care right here, where I can stay connected to mob and family. I want to stay on Country, but they have me travelling for

> specialist. I am so worried I will stay off Country one day ‘cos I am too sick to come back. (Participant 3)

Participants mentioned that many Aboriginal and Torres Strait Islander people do not receive treatment and health care in their communities and on Country and have travel and as a result become isolated from family, kin and other supports within their community. The importance is that each Community is different and may have different services for patients, some patients live in isolated communities with no services and rely on a fly in doctor or fly out form medical services. Participants must travel or relocate for medical treatment, and language becomes a barrier (Jones et al., 2024; Kerr et al., 2024).

Participants noticed that cultural considerations seem to be ignored, translators were not used, and that most health professionals don’t speak Aboriginal and Torres Strait Islander languages. Participants want Aboriginal and Torres Strait Islander staff, and that knowledge and skills are able to be passed down (Kerr et al., 2024). However, the current workforce does not seem to meet the service need, supported by data from participants in this study who frequently had short (or no) interaction with their health professionals when they needed it most. An opportunity present to refocus attention on the priority reforms outlined in the Closing the Gap policy, highlighting the need for greater emphasis on embedding Indigenous knowledges and ways of working and greater focus on developing collaborations with people and organisation who demonstrate appropriate cultural engagement and awareness (Commonwealth of Australia, 2024; Baldwin et al., 2025; Bond & Singh, 2020; Schultz, 2020b).

Participants yarned about health professionals who don't always understand or respect culture or are unable to understand our culture, values and beliefs. An opportunity to address implicit and explicit cultural biases, as highlighted by Hughes et al. (2023). Such an exploration of cultural bias might also contribute to addressing the power imbalances where cultural dominance and racism are still underlining currents, and that some aspects of the health system don't acknowledge culture (Durey, 2010; Gatwiri et al., 2021; Poirier et al., 2024).

Finding strength in relationships with other patients

The importance of yarning about health matters is important, as it gave the participants knowledge and awareness, whilst they supported each other(Geia et al., 2013).. Further development, and formalization, of patient networks would support this element that was seen as an enabler by participants,

Patient networks also have the capacity to reduce the sense of isolation or burden upon others (Health & Welfare, 2024; Liu et al., 2020). While most participants said they continue to rely on family members for support, they also chose to rely on other patients rather than relying on the health system to meet their needs (Hoy et al., 2000; Hoy et al., 2010; Liu et al., 2020). Although several CKD patient networks exist, building the resourcing of these was seen by participants as one way of providing CKD model of care support that works within a cultural framework.

Chapter Summary

Data from this study reinforces the important role health policies, frameworks and strategic plans have on how CKD care and health information is filtered through the system to Aboriginal and Torres Strait Islander patients. Guiding policies and guidelines need to address the specific needs of Aboriginal and Torres Strait Islander patients, and despite having a number of direct policy and practice guidelines, data from participants in this research indicated that the lived experience of gaining health information and support for CKD is still not effective (Dominello et al., 2021; Nagel et al., 2020b). it is essential that health literacy and information must support people's health conditions and be culturally appropriate, and it is important to advocate for support for Aboriginal and Strait Islander people, their families and the community (Dudgeon et al., 2023). Importantly, participant data reflects some of the current research (Baldwin et al., 2025; Council, 2025; Dimopoulos-Bick et al., 2024; Jones et al., 2024; Kerr et al., 2024; Mackean et al., 2025; Tunnicliffe et al., 2024) on working in CKD model of care that engage cultural ways and best meet the needs of Aboriginal and Torres Strait Islander patients.

Chapter 7: Conclusion

This research was to gain an insight into the lived experiences and shared narratives of Aboriginal and Torres Strait Islander participants in relation to their engagement and interaction with the health information and supports provided to them by their health professionals.

This research highlights the experiences of a group of Aboriginal and Torres Strait Islander patients living with CKD as they reflect on the complexities and challenges, they faced in engaging with health resources and supports. It is crucial for patients to have access to resources. It is crucial for patients to have access to resources and information that are both easily accessible and easy to understand and apply to the patients' health needs, that is also clear and straight forward. It is vital to ensure that the focus is on the patient and considers their health conditions and health status. Where the focus also needs to be on the patient centred and material and resources, health literacy needs to be in how disease progress and affects them and what they can do to improve their health outcomes so that they don’t deteriorate, to help identify strategies to improve their health outcomes. This underscores the importance of ongoing research is needed, specifically addressing Aboriginal and Torres Strait Islander needs.

Strengths of this research

The research has several strengths: ethical approval from AH&MRC, an Indigenous researcher and supervisor, and all participants being Aboriginal and Torres Strait Islander. I had the opportunity to build relationships and utilise their words, voices and journeys with a group of Aboriginal and Torres Strait Islander participants.

As an Aboriginal and Torres Strait Islander researcher my use of Indigenous methodology and methods has strengthened my own engagement with the research, and that of the participants. Providing an opportunity for me to also incorporate my own reflexivity, the experiences of being a carer of my mother throughout her CKD treatment, is also a strength as it embeds Indigenous ways of sharing experiences, enabling me to unite Indigenous ways and non-Indigenous ways of information sharing.

Another strength of this research was the positioning of Aboriginal and Torres Strait Islander patient voice as central. Providing scope for patient voices to inform future policy and practice around CKD health information and resourcing encouraged participants to fully share their thoughts and personal health experiences knowing they were doing so in a safe and secure way (that would be heard).

A major strength was the engagement of participants: they assisted me in comprehending their backgrounds, experiences, insights, and perceptions regarding kidney health. The participants permitted me to disseminate their experiences and insights regarding the health literacy, knowledge, skills, information, and advice they received, as well as instances where they were denied access to such resources. They also allowed me to share instances where health professionals withheld health literacy, information, advice, or resources, or where they were unable to access or obtain these resources freely. Additionally, they shared their experiences of being inadequately informed or lacking the necessary knowledge to make informed decisions and understand the progression of the disease. Without their engagement I would not have developed rich insight into some current practices and possible opportunities for change.

Limitations of this research

A potential limitation of the study was the number of participants who took part. It was challenging recruiting Aboriginal and Torres Strait Islander patients whose lives were already very busy juggling both chronic and acute CKD treatments. However, as a master's level study I wanted to profile a cohort of patient experiences, and spend appropriate time with each patient, knowing that each Yarning interview might take double time (or more), as I built the research and data collection around the patient needs and health status.

So, the cohort, within the context of using an Indigenous methodology, and taking time to ensure deep listening, provided me with more than enough qualitative data. The deep listening and in-depth Yarning ensure that I collected every experience they chose to share with me. In some cases, the data was not always aligned to the questions I had asked, but I listened and felt that the participants understood their voices were truly being heard and respected.

Another limitation was the difficulty in recruiting participants, which was due to a number of factors, including the tendency for participants to become unwell and for their condition to deteriorate rapidly, which is a characteristic of the disease. Time constraints also had an impact on the research, leading to the exclusion of some participants. Some participants were hospitalised due to illness, disease, and kidney failure. It was necessary to allow more time for the participants to recover before taking part in the research. This process requires time and entails ethical considerations. It involves implementing sound practices when conducting research with the participants and formulating plans in accordance with their health requirements. Additionally, it ensures gaining an understanding of the plans for managing their health.

Consequently, as a researcher, it was imperative for me to gain an in-depth understanding of the procedures, risks, and considerations pertaining to the participants' limitations due to their health and other needs, given their vulnerability. It was essential for me to respect their rights and to be able to recognise the various signs and symptoms of kidney disease, to facilitate progress, and ensure that each participant received the appropriate care and attention.

In addition, I had to consider the varying needs and timeframes associated with the progression of disease, as each participant was unique and required different levels of support. This involved conducting interviews and engaging in informal Yarning sessions, conversational interactions with the participants, which were crucial for gaining a deeper understanding of their experiences and perspectives.

Given the inherent differences between participants, it is crucial to ascertain when they are well enough to continue the interview. This assessment of vulnerability and unpredictability, coupled with the necessity to extend the research timeline, has led to the submission of multiple extensions. These extensions have been instrumental in supporting my research.

Suggestions for further research

It is possible that improved kidney health literacy and management could have a positively impact on health, and that proactive care could slow the disease progression. It is also possible people could learn new skills and gain a deeper understanding of their care and medication, as well as they can also learn about lifestyle changes that improve health. Prioritise the early stages of CKD and facilitate participation and interaction around health literacy, information, education, resources and advice. A deeper understanding of kidney health could improve individual wellbeing through health literacy, information, education, resources and advice. There is a need for more research on Australians and Aboriginal and Torres Strait Islander people with CKD, and the current research had some limitations in scope, number of participants, design, follow-up, and geographical areas. Additionally, there were knowledge gaps that could be addressed in future studies. The research should be meaningful, beneficial, and led. My current research has facilitated the acquisition of new skills and knowledge in conducting research as a master’s student. This research did not have scope to include nephrologists, health professionals, or nurses employed in nephrology treatment. Nor did it have the scope to include carers. Yarning with both groups provides opportunities for further research beyond this master’s level.

Final comment

My research has progressed and expanded, affording me the chance to gain further opportunities, skills, knowledge, and awareness from a patient's perspective. I developed a close relationship with my supervisor, who encouraged me to adopt a different approach to my research and to focus on the importance of health literacy, information, education, and advice. This approach enabled me to deepen the questions I was asking and to gain a deeper understanding of the importance of appropriate health information on health outcomes. I also used Indigenous methodology and methods to improve my research by applying the knowledge gained from the participants, including insights gained from the yarning and the importance of cultural inclusiveness and language. This was vital for me as an Aboriginal researcher- positioning myself this way in the research and being supported by Indigenous ways of doing research was a great enabler for me.

I have acquired new insights into my role as a researcher, interacting with participants. This master's project has provided me with great learning, a critical personal and academic reflection space, and has inspired me to continue further.

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Appendix 1: Questions asked to the participants for this research

Ethics approved Yarning interview schedule of questions

[Note that the Yarning style is semi structured to allow the interviewee to provide responses as they feel appropriate. It also allows the researcher to explore any point in more depth, that might have been specifically raised by the interviewee.]

- What information have you been given to support your kidney health (renal function)?
- Where did you get the information from?
- Do you feel that the information that has been provided is adequate and meets your needs or have you relied on other sources and resources (e.g. internet)?
- Have you been able to ask more (additional) questions?
- Who have you asked?
- Was this helpful or not?
- What types of information have you received about your kidney care or treatment?
- Where did you get the information from?
- Do you feel that the information that has been provided is adequate and meets your needs or have you relied on other sources and resources (e.g. internet)?
- Have you been able to ask more (additional) questions?
- Who have you asked?
- Was this helpful or not?
- Have you been able to use the information that was given?
- If yes, what made the information easy to use?
- If no, are there any reasons?
- Have you felt comfortable enough to ask further questions about your renal health or treatments?
- Who did you ask?
- What made you feel comfortable to ask more?
- What made you uncomfortable/not ask more?
- Have you felt that you had to “push” to get information?
- Have you felt that you have had time to absorb the information (and been given time)?
- Could you describe if information ever left you confused or uncertain?
- Could you tell me about any times information you were given was given to you in a rushed way?

- Can you describe any types of information you might have received about:
- Good diet to support your renal care (food and drinks)
- Types of care available to you
- Information about your stage of renal health
- Information on what to monitor in your health (*for example* eGFR)
- Any other types of information?
- Could you describe any information about possible complications or risks related to your treatment? (For example, infection, surgery, dialysis)
- Was this information helpful (why/why not?)
- How have you received information about making treatment choices?
- Who was involved?
- What type of information did you get?
- Did you find the information helpful?
- Did you feel educated enough through the information you have received about your renal health and treatments?
- Is there anything else you would like to share with me about the health information you have either received, or hoped you had received?

Appendix 2: Approved participant information form and consent form

Faculty of Medicine and Health

School of Public Health

CHIEF INVESTIGATOR Associate Professor Michelle Dickson	Edward Ford Building Room 326c The University of Sydney NSW 2006 AUSTRALIA Telephone: +61 2 9351 1974Facsimile: +61 2 9351 5205 Email:michelle.dickson@sydney.edu.au Web: http://www.sydney.edu.au/

Health education and information: Lived experiences of renal health patients

PARTICIPANT INFORMATION STATEMENT

You are invited to take part in a research study about the experiences of seeking and using health information related to living as a renal health patient.

(1) What is this study about?

It is important to understand what information is helpful for renal health patients. The study will explore the type of information, the source of the information and the usefulness of information provided to renal health patients. This information will help inform health services and health professionals on how best to meet the health information needs of renal health patients.

You have been invited to participate in this study because you are a renal health patient. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you do not understand or wish to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

Understand what you have read.

Agree to take part in the research study as outlined below.

Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researcher: Ms Louise Graham-Micett (Master of Philosophy student), supervised by Associate Professor Michelle Dickson and Dr Martin Howell, both from the School of Public Health, University of Sydney.

(3) What will the study involve for me?

You will be asked to participate in an Individual interview, done by ZOOM.

You will be asked to participate in an interview, which will focus on your experience of receiving and using health information about renal health. The interview will take approximately 30 minutes and will be scheduled at a time and location that is convenient for you. Questions will focus on how you receive health information, where you receive information from and how useful that information is to you, as a renal health patient. The interview will be audio recorded so we can listen back to your answers carefully.

(4) How much of my time will the study take?

The individual interview will take approximately 30 minutes.

(5) Who can take part in the study?

You can participate in this study if you are 18 years or over and are being supported/treated for your renal health.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by contacting the study coordinator and stating your wish to withdraw from the study.

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we don’t expect that there will be any further risks or costs associated with taking part in this study.

If you do feel uncomfortable or tired, you are able to stop the interview at any time, or tell the researcher that you are feeling worried. The study coordinator can refer you to a community health and wellbeing service if required.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study, however we hope that the findings from this study will be used to raise awareness about the usefulness of different types of information and supports that renal health patients engage with.

(9) What will happen to information about me that is collected during the study?

Your information will be stored securely and your identity/information will be kept strictly confidential. Study findings will be included in the thesis of the researcher (Louise Graham-Micett), but you will not be individually identifiable in this thesis. The thesis will be submitted to the University of Sydney and will be assessed by external public health researchers.

Only information discussed in the individual interview will be used in the study. The interview will be audiotaped and used to identify themes for the analysis of the study. No personal information, including your name, will be used in the final thesis. Third parties will not have access to your contact details or any other information used for the purpose of this study.

Study data and recordings will be stored on the University of Sydney password protected secure data management system. Data will be retained for 5 years and destroyed afterwards.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, the chief investigator, Michelle Dickson, will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Michelle Dickson, chief investigator:

Email: michelle.dickson@sydney.edu.au

(12) Will I be told the results of the study?

We can email you a summary of the findings of the study, if you want this. This feedback will be in the form of a flyer with a summary of the findings. You can opt in to receive this summary on the consent form, if you opt in to participate in the research.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney *[INSERT* protocol number once approval is obtained*].* As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

Telephone: +61 2 8627 8176

Email: human.ethics@sydney.edu.au

Fax: +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

THE UNIVERSITY OF SYDNEY

Faculty of Medicine and Health School of Public Health

CHIEF INVESTIGATOR	Edward Ford Building Room 326c
Associate Professor Michelle Dickson	The University of Sydney NSW 2006 AUSTRALIA Telephone: +61 2 9351 1974 Facsimile: +61 2 9351 5205 Email: michelle.dickson@sydney.edu.au Web: http://www.sydney.edu.au/

Health education and information: Lived experiences of renal health patients

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.

I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.

The researchers have answered any questions that I had about the study and I am happy with the answers.

I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future.

I understand that I can withdraw from the study at any time.

I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don’t wish to answer.

I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I consent to an audio-recording : Yes / No

.... …..
Print Name Date

....
Signature

Opt in for final summary of research findings: yes/no

I would like to receive an email attachment providing a summary of the overall research findings. Please email this to me at this email address:

Email address:

……………………………………………………………………………………………