Bridging the gap: Exploring the use of patient-reported outcome measures in clinical care settings

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Statement of originality

This is to certify that, to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any other degree or purposes.

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

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Authorship contribution statement

The work presented in this thesis has been carried out by the author under the supervision of: Associate Professor Claudia Rutherford of the Susan Wakil School of Nursing and Midwifery, The University of Sydney; Professor Rachael L. Morton of the NHMRC Clinical Trials Centre, The University of Sydney; and Dr Bora Kim of the Daffodil Centre, The University of Sydney.

Chapter 2 (Systematic Review) of this thesis has been prepared as a manuscript and accepted for publication by the Quality of Life Research journal.

I designed the study, extracted and analysed the data, and wrote the drafts of the manuscript.

Chapter 3 (Qualitative Study) has been prepared as a manuscript.

I conducted 11 interviews, analysed all 31 transcripts as the main coder and wrote the drafts of the analysis and manuscript.

As the lead supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

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Associate Professor Claudia Rutherford

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Publications

Publications arising from this thesis:

Chapter 2: **Nikolovski J**, Kim B, Morton RL, Mercieca-Bebber R, Levesque JF, Tinsley M, Sutherland K, Rossiter B, Fagan M, Hartas G, Rutherford C. *Strategies to promote the completion of patient-reported outcome measures by culturally and linguistically diverse and Indigenous Peoples in clinical care settings: a systematic review* (Submitted to Quality of Life Research journal in October 2024 and accepted in December 2024).

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Other publications during candidature:

This thesis informed some key gaps now being addressed in a qualitative study, protocol published as: **Nikolovski, J**., et al., *Acceptability and timing considerations when administering patient-reported outcome measures (PROMs) among people with chronic health conditions who are culturally and linguistically diverse (CALD): a qualitative study protocol.* BMJ open, 2024. **14**(9): p. e083346.

As a consumer advocate, I have been involved in developing patient-reported measures that children and young people can complete without a proxy: Barr KR, **Nikolovski J**, White L, Elliott S, McCartney L, Treadgold C, Vernon B, John JR, Eapen V. *Co-developing a Paediatric Patient Reported Experience Measure: The Perspectives of Children and Young People. Patient Experience Journal*. 2024; 11(3):64-72. doi: 10.35680/2372-0247.1924.

Conference proceedings arising from this thesis:

Event	Format	Title	Date
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Faculty of Medicine and Health Higher Degree by Research Conference	Oral presentation	SWIFT Insights: A qualitative study exploring current symptom monitoring practices in nephrology.	24/07/2024
Faculty of Medicine and Health Early to Mid-Career Researchers' Conference	Oral presentation	SWIFT Insights: A qualitative exploration of symptom monitoring using electronic patient-reported outcomes measures (ePROMs) in nephrology	26/11/2024
Health Services Research Conference, Australia and New Zealand	Oral presentation	SWIFT Insights: Exploring clinicians' perspectives on the use of patient-reported outcomes measures (PROMs) for symptom monitoring in nephrology	04/12/2024
Health Services Research Conference, Australia and New Zealand	Poster	Improving the uptake of patient-reported outcome measures (PROMs) in the routine care of culturally and linguistically diverse (CALD) patients: a systematic review	04/12/2024

Coursework during candidature

- FMHU5002: Introductory Biostatistics
- FMHU5003: Introduction to Qualitative Research in Health
- FMHU5004: Qualitative Analysis and Writing in Health

List of Abbreviations

ACI	Agency for Clinical Innovation
CALD	Culturally and linguistically diverse
ePROMs	Electronic patient-reported outcome measures
EQ-5D-5L	EuroQol-5 Dimensions-5 Levels
HRQL	Health-related quality-of-life
IPOS-Renal	Integrated Palliative Care Outcome Scale – renal
NSW	New South Wales
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRMs	Patient-reported measures
PREM	Patient-reported experience measures
PROM	Patient-reported outcome measures
PROMIS-29	Patient-Reported Outcomes Measurement Information System-29
PROM-PATH	Patient-Reported Outcome Measures Presentation, Acceptability, Timing, Health service use in New South Wales
PROs	Patient-reported outcomes
SPQR	Standards for reporting qualitative research
SONG-HD	Standardized Outcomes in Nephrology in Haemodialysis
SWIFT	Symptom Monitoring wIth Feedback Trial

Abstract

Monitoring symptoms and quality of life can provide important information to clinicians to optimise the management of their patient's chronic condition(s). Patient-reported outcomes (PROs) are patient self-reports on health outcomes such as disease symptoms, treatment side effects, and health-related quality of life. Traditionally used in research settings, there is growing interest in their application in clinical care to enhance communication between patients and clinicians, reduce symptom burden, improve quality of life, and inform health service redesign.

Despite their potential, gaps remain in our understanding of specific strategies to increase PRO measure (PROM) completion by people from culturally and linguistically diverse (CALD) backgrounds and Indigenous Peoples. Additionally, how PROs are captured and actioned in the care of patients with kidney failure is underexplored. Chapter 2 aimed to identify facilitators of PROM completion by people who are CALD and Indigenous Peoples and offer evidence-based recommendations for healthcare providers and policymakers, putting findings in the context of an existing program of PROM collection implemented in New South Wales, Australia. Chapter 3 aimed to understand practices for assessing, monitoring, and managing kidney failure symptoms in Australian haemodialysis units.

This thesis highlights: 1) the limited global strategies to encourage PROM completion by people who are CALD and Indigenous Peoples, and 2) what 'usual care' is for assessing, managing and actioning PROs for patients with kidney failure and why (or why not) PROs are assessed in this context.

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1. Introduction

Chronic conditions are the focus of ongoing public health surveillance, accounting for 74% of deaths globally [1]. Chronic conditions are characterised by persistent and often worsening symptoms lasting at least three months, significantly impacting a person's quality of life [2]. However, the severity, and consequently the impact, of chronic conditions can vary. For example, mild asthma triggered by allergens can be well controlled and without severe complications. On the other hand, chronic obstructive pulmonary disease caused by long-term exposure to irritants (e.g. long-term smoking), can worsen over time, cause long-term functional impairment of the lungs, and be difficult to manage even with treatment [3].

Chronic conditions are the leading cause of illness, disability, and death in Australia [4]. Between 2007 and 2022, the proportion of Australians with at least one chronic condition rose from 42% to 49.9% [5, 6]. The most common four chronic conditions, accounting for 59.6% of all cases in Australia, are mental health and behavioural conditions, back problems, arthritis, and asthma [6]. There is a high proportion of people with more than one chronic condition at the same time, referred to as multimorbidity [7]. Notably, 86.6% of people with chronic obstructive pulmonary disease and 84.4% of people with heart, stroke and vascular disease have another chronic condition [6], which compounds the impact of already high-burden chronic conditions. The rising proportion of Australians with at least one chronic condition can be attributed to multiple factors including aging populations, the globalisation of unhealthy lifestyle habits (e.g., poor diets, low physical activity, consumption of alcohol, exposure to tobacco) and rapid urbanisation [1, 8].

The complexity of treating chronic conditions, the duration of care, and the individual costs of treatment have long placed a significant burden on individuals, their families and carers [9, 10]. Individual-level burdens of chronic conditions include declining quality of life,

costs for treatment, inability to work, and strain on carers [11]. To alleviate the burden on individuals, the provision of care for chronic conditions has shifted over recent decades to focus on helping patients to live well with their chronic conditions.

1.1 Moving from a medical model of care to a person-centred approach

There has been a shift from a medical model of care to a person-centred care approach, in many high-income Western countries, to address the increasing burden of chronic conditions on individuals [12]. Historically, healthcare systems were predominantly focused on acute care, with limited attention to the ongoing management of chronic conditions. Over the past few decades there has been a fundamental change in how healthcare is delivered, moving away from medical models of care towards person-centred approaches to care. This shift has been influenced by broader political and societal changes that emphasise patient rights, empowerment, and autonomy. Political drivers such as universal healthcare systems in several countries and person-centred policies in countries like Australia and the United States have further accelerated this transition.

On an individual-level, a person-centred approach can improve the patient-clinician relationship by recognising the broader social and psychological context of a person's experience with their illness [13-15]. Chronic conditions, like kidney failure, are often incurable and place significant physical and psychological burden on patients that are sometimes poorly addressed in clinical settings. In light of this, acknowledging patients as experts in their health by actively listening to and respecting to their preferences can help guide clinical decision-making [16-20].

1.2 Shifting the role of the patient

As part of a more person-centred approach, some healthcare are referring to patients as ‘healthcare consumers’. The term is commonly used in Australian and United States contexts, particularly in discussions around patient rights, healthcare markets, and the notion of patients as active participants in their own care. It is used to highlight the evolving role of individuals in making decisions about their care and the growing emphasis on patient choice and autonomy [21]. Active healthcare consumers do not take first recommendations from healthcare providers but may seek several opinions, ask questions, and weigh their options to decide on the best course of action for them [22, 23]. In contrast, many other countries, particularly in Europe, prefer the term "patient" to describe individuals receiving healthcare. This discrepancy in terminology reflects different healthcare system philosophies and patient roles in the healthcare process. As the term ‘consumer’ has yet to be consistently used on a global scale in the literature, ‘patient’ will be used in this thesis to refer to individuals receiving care for chronic condition(s).

1.3 Shift from acute care to primary care settings

Historically, the management of chronic conditions was confined to hospitals and specialised clinics, with patients often receiving care only during acute episodes or complications. The growing prevalence of chronic conditions has led to increasing demands on hospitals, resource limitations and managing multimorbidity. Therefore, it is necessary to find cost-effective models of care to identify those at highest need to intervene early by reducing complications of treatment and improving overall health [24]. Managing chronic conditions effectively can lead to fewer clinic visits, hospitalisations, and laboratory and diagnostic tests.

Cumulatively, this reduces healthcare resource use and total medical costs associated with managing chronic conditions [25].

1.4 Patient-Reported Outcomes (PROs)

Monitoring patient-reported symptoms and quality of life can provide important information to clinicians to optimise the management of chronic conditions. Patient-reported outcomes (PROs) are "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [26]. Commonly assessed PROs include symptoms, treatment side effects, and health-related quality of life (HRQL) [27].

Over the past two decades, there has been a growth in the use of patient-reported measures (PRMs) to better understand a patients' preferences and guide clinical decision making. PRMs include patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs), where the former focuses on a patients' perception of the quality of the healthcare they have received.

Organisations such as the European Medicines Agency, the International Consortium for Health Outcomes Measurement, the United States (US) Centers for Medicare & Medicaid Services, the US National Institute of Health, and the US Food and Drug Administration endorsed the expansion of PROMs into clinical care settings. In Australia, PROM collection and use are supported by the Australian Government and leading health bodies such as the Agency for Clinical Innovation (ACI; a branch of NSW Health), The Australian Institute of Health and Welfare (AIHW) and the Australian Commission on Safety and Quality in Health Care (ACSQHC). The latest Australian Health Performance Framework features the broader uses of PROMs to assess the appropriateness and safety of care [28].

PROMs are questionnaires or surveys that quantify PROs with numerical scores [29] and have been widely endorsed and used for decades in clinical trials as important trial endpoints. Early randomised controlled trials in oncology evaluated the impact of web-based collection of PROs, with automated alerts to clinicians for severe or worsening symptoms [30, 31]. One study found that patients who reported PROs at home experienced greater reductions in symptom events than controls (19% and 8% respectively) during the four weeks after surgery [31]. Another trial showed evidence that patients who reported PROs via email between clinic visits had: improved HRQL and survival, fewer visits to emergency departments, fewer hospitalisations, and remained on chemotherapy longer compared with patients receiving usual care [30]. This was because nurses intervened to address concerning PROs through telephone counselling, adjustment to medications and hospital referral [30].

PROMs can be categorised into two types: generic and condition-specific [32]. Generic PROMs, such as the PROMIS-29, are designed to measure broad aspects of health and can be used across different populations and health conditions. These measures assess domains such as physical functioning, mental health, and general well-being, providing a comprehensive view of a patient's health. As implied by their name, condition-specific PROMs intend to offer more detailed insights into how a particular disease or health condition affects a patient's daily life. An example is IPOS Renal- a set of 11 questions combining the most reported symptoms that patients with kidney failure experience. The use of both generic and condition-specific PROMs can provide a more complete picture of patient outcomes by understanding how someone experiences life and perceives their quality of life with their chronic condition(s).

There is enthusiasm for collecting PROMs in clinical care settings for the ongoing management of chronic conditions- to improve the diagnosis and recognition of symptoms

and to align patient and clinician goals. PROMs can serve as a screening tool for psychosocial factors, assisting in diagnosing conditions, tailoring care to the individual and prompting appropriate action [33]. Using PROMs in routine practice encourages the patient's voice [34] by: 1) improving how patients communicate their symptom burden and treatment effects with their clinicians [35], 2) shifting the attention of the clinical encounter to addressing symptoms and treatment outcomes that matter most to patients [33, 34, 36], 3) aligning goals between patients and clinicians [37] and 4) helping patients to ask clinicians specific questions [36, 38]. The time taken to complete PROMs allows patients to pause and reflect before their consultation [33, 39], describe uncomfortable topics [33, 34], prompt memory of their symptoms [33, 36, 38] and bring awareness to issues they may not have considered [34]. By providing a structured framework for patients to express their concerns, preferences, and priorities, PROMs help bridge the gap between patient experiences of their symptoms and other clinical assessments (e.g., blood tests).

Some patients report feeling healthier, more hopeful and better supported when PROMs are used in their care [34], which can help address some of the psychosocial burden of chronic conditions. Some patients also report they are more aware of how they can improve their own situation [34] and reduced anxiety during consultations [36].

PROMs should not be treated as a “tick box”- they are valuable when discussed during clinical encounters [37]. When clinicians refer to their patient’s completed PROM, it communicates that completing PROMs is not a waste of time [39]. Patients feel taken care of, taken seriously, and reassured that their clinicians care [34]. Clinicians report that patients appear relieved when their PROMs data are used as they are listening to what is most important to patients [36]. Patients are also more likely to rate their service quality as excellent and that their healthcare provider understood their needs [34].

1.5 Methods of PROM completion

Patients prefer to choose the method by which they complete PROMs based on convenience, technology proficiency, physical limitations, staff and family support available to complete PROMs, and other contextual factors [38].

1.5.1 Paper-based PROMs

PROMs are traditionally measured using pen-and-paper questionnaires but are associated with unreadable, missing, or faulty data [40] and require administrative support in storing or uploading data to digital systems for viewing and actioning by clinicians. Nevertheless, some patients prefer paper-based PROMs as they would like to see previous questions or have more time to complete their PROMs [38, 39]. The data from PROMs cannot be easily interpreted at a glance at the point-of-care, and PROM data collected across time cannot be visualised to understand changes to health outcomes [41].

1.5.2 Electronic PROMs

There are additional modalities to complete PROMs, including over the phone, or electronically on a tablet or computer. The growth of electronic PROMs (ePROMs) is facilitated by the increasing integration of technology in healthcare and patients wanting to use more innovative ways of managing their health [42]. ePROMs enable immediate reporting of results, increased data quality, decreased time to complete, less paper waste and costs, and automated reminders and workflow [38, 41]. Patients also enjoy the convenience of either completing ePROMs at home (with fewer disruptions) or whilst they wait in clinics for their appointments (if they require staff assistance) [39]. Studies report that patients find web-based PRO systems acceptable and easy to use, even if they have minimal prior experience with technology [30, 38]. ePROMs are now also developed to have multilingual

functions to be used across languages, and evaluations of user satisfaction suggested that patients and clinicians generally accept ePROMs with multilingual functions [43].

PROMs are not just beneficial for a snapshot of a patient's health at one point in time. Patients, carers and healthcare staff report the usefulness of having many scores to understand patients' health outcomes over time [37, 44, 45], including graphs to visualise data [29]. Comparing scores over time can help assess whether treatment is improving or negatively affecting symptoms and HRQL. Nurses reflect that the visual display of ePROMs allows concerning and improving scores to be pertinent, providing them with the ability to have a "quick glance" before consultations [34]. Visual displays are also helpful for patients and carers who would like to monitor patterns [33, 36], but there is a need to modify displays to improve the interpretation of scores, particularly the meaning of numbers and comparison groups [32].

The implementation of ePROMs in routine care is not without its challenges at individual and service levels [41]. There is mistrust among some patients regarding the protection of their data including who has access to their data [39]. There are technical issues for patients and staff who are trying to access and complete PROMs, and a divide between those who have higher technology literacy and people who may not have access to the knowledge or technology to access or complete PROMs electronically [41]. Therefore, ePROMs may exclude certain populations who are older, have poor digital literacy, or have no internet access or technological devices [41].

1.6 Patient-level barriers to PROM implementation

Some patients believe PROMs are collected as a time-saving exercise for clinicians (by reducing the time taken to ask symptom questions) and used to reduce costs for the clinic,

whilst others thought they were solely used for research [38]. Completing PROMs can be a stressful experience for some patients who are worried about responding correctly. For example, patients have concerns that if they were honest about feeling better on any given day, then their medication or care would be withdrawn [38]. Due to the long-term burden of chronic conditions, patients struggle to quantify their symptoms as they become accustomed to living with their condition(s), which may lead to over or under-reporting symptoms.

1.7 Overcoming clinician-level barriers to PROM use

Since PROMs were implemented in routine care in the mid-1990s, clinicians have reported several attitudinal, practical and systemic barriers to their use in routine care settings [34]. The main criticisms reported in systematic reviews are: PROMs have little benefit relative to the time and resourcing required, clinicians question the accuracy of patient self-reports, and PROs reported in generic PROMs may not provide clinically meaningful or actionable data compared to condition-specific PROMs [37, 46]. There is also concern that PROMs are often completed in English (or the countries' native language) and excludes culturally and linguistically diverse, elderly, low-literacy, and cognitively impaired patients.

Some barriers have been reduced by the development of ePROMs, clinician's increased experience in using PROMs, evidence of improving patient-clinician relationships, improved perceptions of care, patient adherence to treatment, and the timeliness in which potentially concerning symptoms and treatment side effects can be identified [41]. The use of PROMs in routine care settings can be facilitated by technological infrastructure, the ability to compare scores across clinics and services, and training staff well [37, 45].

1.8 Priority populations

Healthcare encounters between clinicians and patients from diverse cultural and linguistic backgrounds are increasingly commonplace in the context of a multicultural society. However, Indigenous Peoples and people from a culturally and linguistically diverse (CALD) background are disproportionately affected by chronic conditions and a combination of social, cultural, historical, and systemic factors contributes to lower quality of care [47, 48]. Language barriers, lack of social support, lower levels of health literacy and a sense of disempowerment exacerbate inequalities in healthcare access. Further, Indigenous Peoples and people from a CALD background may have different conceptions of health, illness, and healthcare which can heighten inequalities and increase the risk of adverse safety events [47-50]. To address these known barriers, and work towards reducing inequity in healthcare, we can provide opportunities for patients to provide feedback on their health to direct care via health initiatives such as PROMs. However, the underuse of targeted, culturally specific and culturally appropriate approaches is lacking, contributing to an underuse of PROMs in these communities.

1.9 Culturally and linguistically diverse populations

Australia is one of the most culturally diverse countries in the world [51], predominately because about 31% of our population are migrants [52]. The proportion of the Australian population born overseas is increasing- in 2021, 27.6% of the Australian population were born overseas, compared to 26.3% in 2016 [53]. Coincidingly, those speaking a language other than English have risen from 21.6% in 2016 to 22.8% in 2021 [53].

1.9.1 Defining 'CALD'

In 1999, The Australian Bureau of Statistics introduced the term "Cultural and Linguistic Diversity" to draw attention to multicultural populations in Australia, with a range of linguistic and cultural characteristics. This thesis defines CALD status as people born in non-English speaking countries, and/or who do not speak English at home and/or have limited English proficiency (LEP) and/or are from a racial or ethnic minority.

Each CALD community are diverse culturally, linguistically, religiously and socially [54]. This includes coming from different migrant backgrounds as refugees, asylum seekers, temporary migrants (e.g., temporary work-skilled, international students), permanent residents and citizens (first or second-generation migrants) [55]. Over 200 languages are reportedly spoken in Australian homes [56], with the most common languages, besides English, being Mandarin, Arabic, Vietnamese and Cantonese [57].

1.9.2 Health outcomes in CALD populations

Over time, it has consistently been reported that people from a CALD background have poorer survival outcomes and HRQL [53]. Their psychological well-being is poorer, with a higher prevalence of depression, which may be exacerbated by experiences of trauma (e.g., leaving war-torn countries) [54] and not understanding or mistrusting a foreign healthcare system [55]. Clinicians report it is harder to assess and manage pain as patients struggle to communicate the extent and impact of their pain on their daily lives due to language and/or cultural factors (i.e., some topics are not culturally acceptable to discuss) [56].

Some immigrant groups anticipate social stigma and, therefore, rely on self-help rather than seeking assistance from healthcare providers [57]. These patients reflect that their clinicians empathise very little with their social context and thus do not understand the nature

of their concerns. Muslim women report similar cultural insensitivities from their healthcare providers, such as a poor understanding of religious and cultural needs [55].

Language barriers negatively impact the quality and safety of care globally [58] and there are low levels of participation from people from a CALD background in clinical trials and research generally. One contributing factor is uncertainty when reviewing information and consent documents. This includes the use of medical and legal jargon rather than everyday terminology, a poor understanding of risks and the nature of the procedure, and document formatting that is difficult to follow [59]. In clinical settings, there is linguistic and cultural incompatibility when communicating with healthcare teams, especially during short consultations with clinicians [55, 60, 61]. Even if patients from a CALD background speak enough English to navigate day-to-day activities, can be difficult to express themselves in a healthcare context, particularly when describing pain and medical terminology [54, 62] and understanding health concepts (health literacy).

1.9.3 PROMs completion in CALD populations

Literacy levels. The barriers to PROM completion and use are more challenging when considering the context of patients who are CALD. The growing emphasis on person-centred care has increased the reliance on PROMs to understand health outcomes. However, this shift may exacerbate health inequalities if the specific needs of minority populations are not considered during PROM implementation. For example, PROMs completion and comprehension of PROM data require high levels of English and health literacy. Rates of poor literacy and health literacy are higher in CALD populations [68, 69]. Inadequate health literacy is associated with poor health status and more strongly predicts poor health than age, income, employment status, education level or race [70]. Furthermore, a person's health literacy and health status can affect their capacity to self-manage chronic conditions [59].

Obtaining culturally and linguistically appropriate PROM translations. The cultural insensitivity of translated PROMs presents a significant challenge in their completion and use. It is not just about translating into different languages, but also about culturally adapting them to ensure acceptability among key end-users, such as patients and clinicians [71]. Cultural and linguistically validated translations are crucial for applicability in research and clinical settings. Sometimes, there are no equivalent terms for certain words in different languages, so substitute terms should be negotiated using professional translators, but this may not be available due to resourcing constraints. In a cohort of surgeons, some participants noted that English PROMs translated by interpreters during clinical encounters were better than no collection, but the availability of standardised PROM translations is important when comparing PROs across patients speaking different languages [72].

In a qualitative study, many surgeons who use PROMs during appointments with patients describe high completion rates amongst English-speaking patients, contrasting the routine exclusion of patients who have poor English proficiency and the prominent barriers they face in completing PROMs [72]. Most electronic PROM interventions are designed for and targeted to English-proficient populations. However, CALD populations recognise the importance of PROMs for their health and broader research and are willing to learn how to use PROMs data if there is appropriate staff support [73]. Increasing resourcing for PROMs in other languages can help to manage communication gaps between patients and clinicians, aligning treatment and management goals and identifying adverse treatment effects.

1.10 Indigenous Peoples of Australia

1.10.1 Defining Indigenous Peoples

Indigenous peoples are the original inhabitants of a particular region or territory, with distinct cultural, social, and historical identities that are rooted in the lands they have traditionally occupied. They often have unique languages, customs, spiritual beliefs, and systems of governance that have been passed down through generations. Indigenous peoples have a deep connection to their ancestral lands and natural resources, and these connections shape cultures and practices. While different terms have been used to refer to Indigenous Peoples globally (e.g., in Australia: Aboriginal and Torres Strait Islander peoples, indigenous Australians/peoples, Australia's indigenous peoples, First Nations, and traditional owners), the term "Indigenous Peoples" will be used throughout this thesis when describing these communities.

1.10.2 Health inequities experienced by Indigenous Peoples

Over one million Indigenous Peoples live in Australia, accounting for almost 4% of the population [74]. There are major health disparities between Indigenous Peoples and non-Indigenous Peoples. For example, in Australia, Indigenous People's life expectancy at birth is 8.8 years lower for males and 8.1 years lower for females compared to non-Indigenous Peoples [75]. Indigenous Peoples in Australia experience higher rates of chronic conditions than non-Indigenous Peoples, especially mental health and substance abuse disorders and injuries [76]. They also report several barriers to accessing healthcare to manage or treat chronic conditions. Indigenous Peoples are often geographically isolated, living on traditional lands occupied by their ancestors, and away from metropolitan regions where health services are concentrated [77]. Further, available health services are not always culturally safe

environments and unsuitable for the unique needs of Indigenous Peoples. For example, they may lack infrastructure and resources such as Indigenous health workers, community engagement in the design and implementation of health initiatives and holistic healthcare that incorporates cultural practices and values [78].

Current health inequities experienced by Indigenous Peoples in Australia are attributed to the historical and ongoing effects of colonisation, dispossession of land, cultural suppression, and ongoing marginalisation [79, 80]. These experiences have led to intergenerational trauma, socio-economic disadvantage, and a loss of traditional healthcare practices, all of which contribute to poorer health outcomes [79, 80]. The danger of limited access to healthcare, lack of culturally competent care, and mistrust of healthcare systems is that Indigenous Peoples either present later for care, do not receive medical care at all, or receive poor quality, culturally inappropriate or unsafe care [81]. Positive influences for Indigenous Peoples' health and well-being are mainly cultural factors such as connection to and caring for country, knowledge and beliefs passed down through generations, and the importance of family and language [79].

1.10.3 PROMs designed for Indigenous Peoples

There are limited examples of PROMs specifically designed for Indigenous Peoples, including domains relating to culture, diet and land use alongside traditionally measured HRQL domains [82]. One systematic review of global evidence of PROMs used in Indigenous populations reported only three of 41 studies used PROMs specifically designed for Indigenous Peoples, alluding to the notion that Indigenous Peoples' preferences and understanding of health are not incorporated into clinical decision-making [82]. The absence of validated PROMs, and the paucity of evidence about how to increase PROM completion by Indigenous Peoples, presents a significant gap in healthcare and the literature. Indigenous

Peoples often face unique health challenges and cultural contexts that are not adequately captured by standard PROMs [83]. This lack of tailored measures can lead to underrepresentation and misinterpretation of their health outcomes and experiences and highlights the need for health services that are responsive to the needs of Indigenous Peoples.

The British Columbia SUPPORT Unit Patient-Centred Measurement Methods Cluster, part of Canada's Strategy for Patient-Oriented Research have recommended 13 ‘protocols’ that should be followed to develop PROMs that are culturally appropriate for, and beneficial to, Indigenous Peoples [84]. In summary, building trust between researchers and Indigenous Peoples from ‘end-to-end’ includes: building the study team; involving ceremony and storytelling in all stages; identifying Indigenous Peoples’ priorities; inviting Indigenous community members, leaders and experts in the design of content; validating PROMs to ensure cultural appropriateness, relevance, reliability, validity; administration in culturally appropriate methods (e.g. verbally in-person or over the phone); triangulating data analysis to include Indigenous and western worldviews; and ensuring results are shared with the community and communicating how changes are implemented. Now that guidelines have been developed for co-designing culturally appropriate PROMs for Indigenous Populations, it is important to understand strategies to promote the completion of PROMs by Indigenous Populations, which is poorly reported in published literature.

1.11 Importance of this thesis

There is a paucity of global strategies to increase PROM completion and use by people from CALD backgrounds and Indigenous Peoples with chronic conditions. Given the exclusion of these populations in PROMs initiatives, and the reported benefits of PROMs in routine care, it is important to ascertain strategies available to promote PROM completion in these populations. This gap in current research highlighted the need to conduct a systematic review

(Chapter 2) to determine strategies used globally to increase the completion of PROMs by people who are CALD and Indigenous Peoples.

Chapter 3 fills our gap in understanding how symptoms are assessed, monitored and acted upon in a haemodialysis context. Exploring the use of PROMs in haemodialysis settings can contribute knowledge about how symptoms can be better addressed to facilitate person-centred models of care for patients with kidney failure.

1.12 Research questions

To address existing knowledge gaps, this thesis asks:

1) What strategies can promote the completion of PROMs in CALD and Indigenous populations?
2) How are patient-reported symptoms assessed, monitored and actioned in haemodialysis centers in Australia?

1.13 Research aims:

1. To synthesise existing evidence about facilitators to PROM completion by CALD and Indigenous Peoples.
2. To make recommendations about how to increase PROM completion by CALD and Indigenous Peoples.
3. To understand how PROs are assessed and monitored for patients with kidney failure in Australian haemodialysis centres.
4. To understand how symptoms are monitored in haemodialysis centres with a population of CALD and Indigenous Peoples.

1.14 References

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2. Promoting PROM completion

Chapter 2 presents a systematic review synthesising strategies to promote the completion of PROMs by people who are culturally and linguistically diverse (CALD) and Indigenous Peoples in clinical care settings. There is potential for people from CALD backgrounds and Indigenous Peoples to provide feedback on their health *via* PROMs to direct care.

In this study, people from CALD backgrounds and Indigenous Peoples were prioritised their health needs are often not adequately addressed within mainstream healthcare models. By prioritising these populations, this research aims to contribute to the development of strategies that can enhance the cultural competency of PROMs, increase patient empowerment, and ultimately improve health outcomes for patients from diverse backgrounds.

A strengths-based approach was adopted for this review because of the potential of patients to actively contribute to the direction of their own care, leveraging their unique knowledge of their health and experiences. This approach recognises that patients, particularly from CALD and Indigenous communities, possess valuable insights into their wellbeing and that involving them in the decision-making process can lead to more personalised, effective care. When patients are empowered to provide feedback on their health, such as through PROMs, it can facilitate a deeper understanding of their symptoms, preferences, and goals. This is especially important in chronic conditions where managing symptoms and improving quality of life requires ongoing communication and collaboration between patients and healthcare providers.

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Strategies to promote the completion of patient-reported outcome measures by culturally and linguistically diverse and Indigenous Peoples in clinical care settings: a systematic review.

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2.1 Abstract

Purpose

There is evidence of low completion of patient-reported outcome measures (PROMs) by culturally and linguistically diverse (CALD) and Indigenous populations with chronic health conditions. We aimed to systematically identify ways to support and promote PROM completion by CALD and Indigenous Peoples in clinical care settings.

Methods

We searched Medline, Embase, Scopus, Web of Science Core Collections and CINAHL databases from 1 January 2000 to 19 September 2024. Primary studies were included if they focused on strategies/enablers of PROMs use in the care of CALD and Indigenous populations in clinical care settings. The quality of included papers was appraised independently by two reviewers, using the Critical Appraisal Skills Programme (CASP) and Mixed Methods Appraisal Tool (MMAT). Data were analysed thematically. PROSPERO registration: CRD42023469317.

Results

Of 13,450 title/abstracts retrieved, five papers met eligibility. Strategies to promote PROM completion by Indigenous Peoples included 1) providing training to patients about what PROMs are and 2) offering verbal modes of completion and 3) community consultation during design, development, and implementation of PROMs to ensure culturally appropriate and sensitive PROMs are used. Strategies to increase completion amongst CALD populations included 1) providing information about how to use electronic PROMs, 2) facilitating self-completion, 3) offering different modes of completion (paper-based, digital), and 4) increasing availability and system-wide support of culturally and linguistically appropriate PROM translations.

Conclusion

Few studies reported strategies to increase the completion of PROMs by CALD and/or Indigenous Peoples. Adequate training, planning (including community consultation), resourcing, and financial support are required to encourage CALD and Indigenous Peoples to participate in PROM initiatives globally.

Keywords

Patient-reported outcome measures; clinical care settings; culturally and linguistically diverse; Indigenous Peoples; systematic review

2.2 Plain English Summary

People from culturally and linguistically diverse (CALD) backgrounds and Indigenous communities often struggle to complete health surveys about how they feel, function and live their lives with their health conditions. This study looks at ways we can support people to complete health surveys.

We found that we can help Indigenous communities complete health surveys by teaching them about what health surveys are used for, offering verbal completion, and involving the community in designing health surveys. For people from a CALD background, useful ways included providing information about electronic health surveys and how to complete them.

Our findings highlight that patients and healthcare staff need more training, community involvement is important, and more resources are needed to improve health survey completion by people from CALD and Indigenous backgrounds to ensure that their voices are included in healthcare decision-making.

2.3 Introduction

Chronic conditions are long-lasting and persistent medical conditions that impact a person's health-related quality of life (HRQL) [1] and are responsible for 74% of all deaths globally [2].

CALD and Indigenous Peoples experience higher rates of chronic conditions and worse health outcomes over time compared with their English-speaking counterparts [3], including poorer survival outcomes [4], HRQL and psychological wellbeing [5], and increased risk of hospitalisation and emergency department visits [6]. CALD and Indigenous Peoples are historically marginalized, underserved and underrepresented in healthcare policy and decision-making [7-10].

2.3.3 Defining CALD and Indigenous Peoples

The Australian Bureau of Statistics, in 1999, introduced the term "Cultural and Linguistic Diversity" to draw attention to multicultural populations in Australia, with a range of linguistic and cultural characteristics. In this study, CALD refers to people born in non-English speaking countries, and/or who do not speak English at home and/or have limited English proficiency (LEP) [25].

Different terms have been used to refer to Indigenous Peoples such as Aboriginal and Torres Strait Islander peoples, indigenous Australians/peoples, Australia's indigenous peoples, First Nations, and traditional owners. For consistency when reporting findings about individuals, the term "Indigenous Peoples" will be used [25].

2.3.1 Contributing factors of poor health status for CALD populations

People who are CALD may have poor access to high-quality medical advice due to socioeconomic factors such as distance from their home to health services, availability of culturally appropriate health services, and out-of-pocket costs [11].

Poorer health outcomes within CALD populations may be exacerbated by linguistic and cultural incompatibility during clinical encounters [12, 13]. Even when people speak a reasonable amount of English, it can be difficult to describe health concerns like pain [11], and to understand medical terminology [11, 14]. Healthcare professionals also find it harder to assess and manage People from a CALD background's symptoms due to communication barriers [15] and overestimating their patient's level of English proficiency [16].

2.3.1 Contributing factors of poor health status for Indigenous Peoples

Systematic review of disparities in healthcare services amongst Indigenous populations in North America, Australia and New Zealand highlight contributing factors such as rural location and socioeconomic status contribute to poorer accessibility of health services [17]. Cultural conflicts between Western medicine and native spirituality on Indigenous People's view of health and wellbeing [17] can lead to mistrust and underutilization of healthcare services, further exacerbating health disparities.

2.3.2 Improving quality of life for CALD and Indigenous Peoples

Patient-reported outcome measures (PROMs) enable the collection of self-reported information from patients about their health condition without interpretation from anyone else [18] and assess outcomes such as disease symptoms, treatment side-effects, and HRQL [19, 20]. In clinical practice they can be used to facilitate communication between patients and their clinicians [21] and monitor responses to treatment over time [22].

In clinical care settings, there are low PROM completion rates by CALD and Indigenous populations [23]. This means evidence informing clinical decision-making and medicines regulatory decisions often exclude CALD and Indigenous People's voices, impacting the validity and generalisability of research findings as participant samples often fail to represent diverse populations [24].

2.3.4 Study Aim

By synthesizing existing research, this systematic review aims to 1) identify ways to support and promote PROM completion by CALD and Indigenous Peoples and 2) use findings to offer evidence-based recommendations for healthcare providers and policymakers and 3) put findings in the context of an existing program of PROMs collection implemented in New South Wales, Australia.

2.4 Methods

This systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (see Supplementary File 1) [26] and was registered on PROSPERO: CRD42023469317. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation/Outcome, Research type) tool was adopted to define key elements of the review question and inform the search strategy [27].

2.4.1 Electronic searches

A comprehensive search strategy was developed by JN with advice from the project team and iterative consultations with an academic liaison librarian at the University of Sydney. The search was conducted by JN in Medline, Embase, Scopus, Web of Science Core Collections and CINHAL databases from 1 January 2000 (the year that PROMs were introduced in the United States as a reimbursement tool for healthcare organisations [28]) to 19 September 2024 (date data extraction and analysis was completed). Alerts were enabled to inform any

new studies up until data extraction and analysis was finalised. The search strategy included population terms such as “culturally and linguistically diverse”, “Non-English Speaking Background”, “Indigenous Peoples”; intervention terms such as “patient-reported outcome”; outcome terms like “strategies”; and study design terms like “qualitative” and “mixed methods”. These concepts (population, intervention, outcome, and study design) were combined using the Boolean term “AND”. There were no language or country restrictions. See Supplementary File 2 for the full search strategy.

2.4.2 Study selection and eligibility criteria

Retrieved papers were assessed against the eligibility criteria outlined in *Table 1.*

Table 1. Inclusion and exclusion criteria used to screen eligibility of identified studies using SPIDER **(Sample, Phenomenon of Interest, Design, Evaluation/Outcome, Research type) tool**

Aspect	Inclusion criteria	Exclusion Criteria
Sample	• Population are people of a CALD background, defined as people born in non-English speaking countries, and/or who do not speak English at home and/or have limited English proficiency (LEP) *or* • Population are Indigenous Peoples, defined as the first and original inhabitants of the country in which the study is set *and* • Adult CALD and/or Indigenous Peoples with a chronic condition, or healthcare staff treating patients with chronic conditions, defined as a condition that persists and/or requires ongoing surveillance/monitoring and/or treatment and/or worsens over time and/or patient experiences long or late-term effects of treatment *or* • Healthcare staff who use translated PROMs and/or use PROMs for CALD and/or Indigenous peoples	• Population: <18 years of age and/or not CALD or Indigenous and/or does not have chronic condition.
Phenomenon of interest	PROMs completed in clinical care settings. PROMs defined as self-reported information from patients about their health condition without interpretation from anyone else[18] and assess outcomes such as disease symptoms, treatment side-effects, and health-related quality-of-life	• Focused only on PREMs, not PROMs.
Design	• Qualitative, quantitative, mixed-methods, cohort	• n/a

Outcome	• Attitudes, perspectives and experiences of using PROMs	• Focus on validation of PROMs, hypothetical scenarios generated (PROMs not implemented).
Research type	• Primary, peer-reviewed research	• Reviews, editorials.

Abbreviations: CALD: culturally and linguistically diverse; PROMs: Patient-reported outcome measures; PREMs: patient-reported experience measures.

1

2.4.3 Screening

Search results from all databases were downloaded into Endnote 20 [29]. Following de-duplication, remaining citations were exported into Covidence, a data management software used for systematic reviews (Veritas Health Innovation, Melbourne, Australia) [30]. One reviewer (JN) screened all retrieved titles and abstracts against the eligibility criteria. A second reviewer (BK) randomly screened 20% against the eligibility criteria to ensure inter-rater reliability. An *a priori* strategy was used where a threshold of 10% discrepancy was set; if discrepancies exceeded this level, an additional 10% of articles would be screened. The discrepancy rate between the first and second reviewers for the randomly selected 20% of articles was <1%. Studies eligible for full-text review were independently assessed by JN and BK. Any disagreements about study eligibility were discussed between reviewers until consensus was reached. Any disagreements were discussed with a third reviewer (CR). Study selection is summarised in the PRISMA flow chart (See Figure 1).

To ensure no potentially relevant papers were missed, JN searched the reference lists and authors of included papers. No additional papers were added from these searches. One full-text paper in Spanish was translated into English by the University of Sydney Library.

2.4.4 Data Extraction and Synthesis

Though some definitions of 'CALD' encompass Indigenous Peoples, we have synthesised and reported evidence for Indigenous Peoples separately as they are the first and original inhabitants, contributing uniquely to cultural and linguistic diversity in their respective countries.

Data were extracted using a predetermined table in Microsoft Excel, including headings such as "information about PROM(s) used in the study", "participants", "qualitative

framework", "study methods", "data analysis", "strategies for PROM completion" and "perspectives and experiences of using PROMs".

Thematic analysis was used to synthesise qualitative findings [31]. Microsoft Word was used to group strategies to PROM completion from each paper, including representative quotes. Via an iterative process, JN and CR developed themes, and all authors were consulted to capture a range of clinical and health-service perspectives about the data.

2.4.5 Assessment of methodological quality

To assess the methodological quality of qualitative studies, the Critical Appraisal Skills Programme (CASP) [32] assessment tool was chosen as it is a widely used tool for quality appraisal in health-related qualitative research, endorsed by the Cochrane Qualitative and Implementation Methods Group and recommended for novice qualitative researchers [33]. There are 10 questions across three sections with 'yes', 'no' and 'can't tell' options: (A) Are the results of the study valid? (B) What are the results? (C) Will the results help locally?

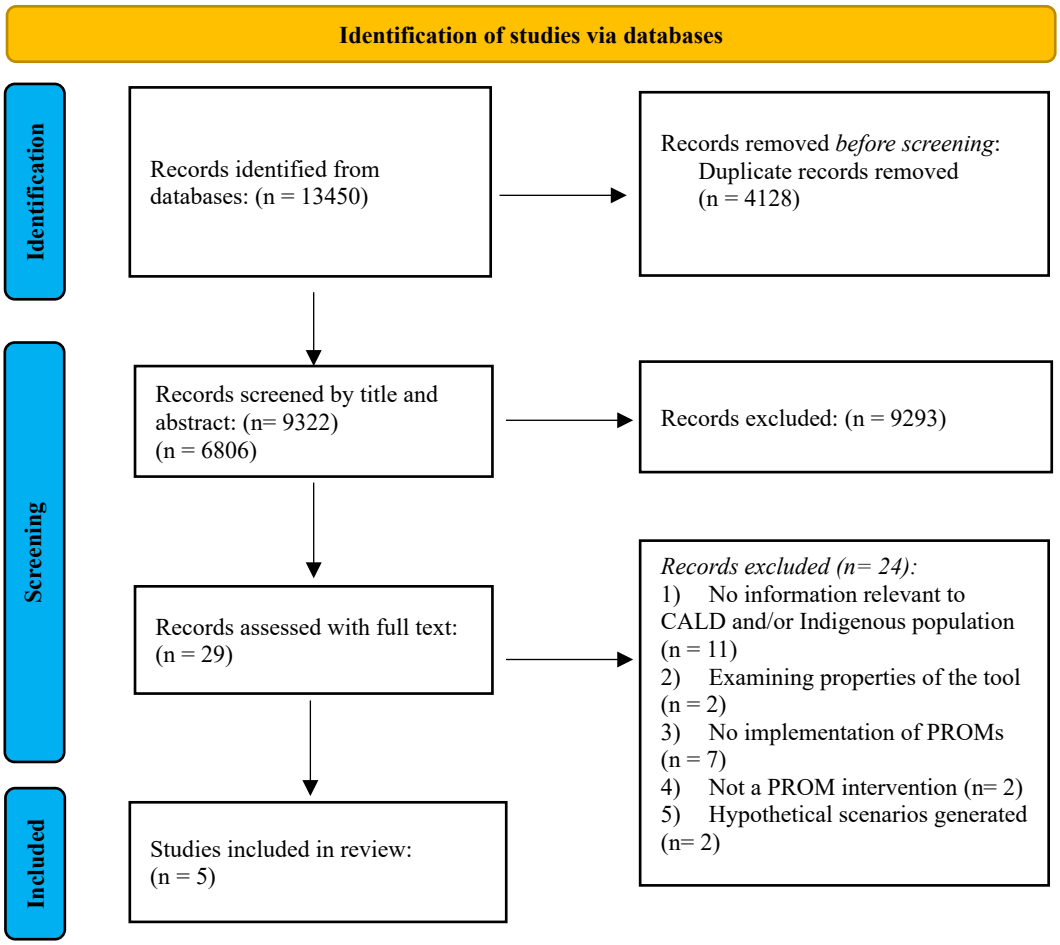
To appraise the quality of mixed-method studies the Mixed Methods Appraisal Tool (MMAT) was used as it was developed for mixed-method systematic reviews [34]. There are five methodological quality criteria rated with 'yes', 'no' and 'can't tell' options.

2.5 Results

2.5.1 Study inclusion

Three authors were contacted for further information to determine eligibility; these studies were excluded due to non-response (n=2) or not meeting eligibility criteria (n=1).

Figure 1: *Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow-diagram of included papers.*



2.5.2 Summary of included Papers

Characteristics of the included papers are described in *Table 2*. Five studies were included which were conducted in the United States (n=3) [35-37], Australia (n=1) [38] and Europe (n=1) [39] across a range of care settings, including academic, outpatient, inpatient and community centres. PROMs used in studies included PROMIS-29 [38], PAID [38], and MoPat2 [39] (specifically designed for the study). Three studies did not report which PROMs were used [35-37].

Study designs included qualitative (n=4) [35-38] and mixed methods(n=1) [39]. CALD patient perspectives were reported in four studies [36-39] and perspectives of healthcare staff were reported in two studies [35, 39].

Table 2. Summary of included papers.

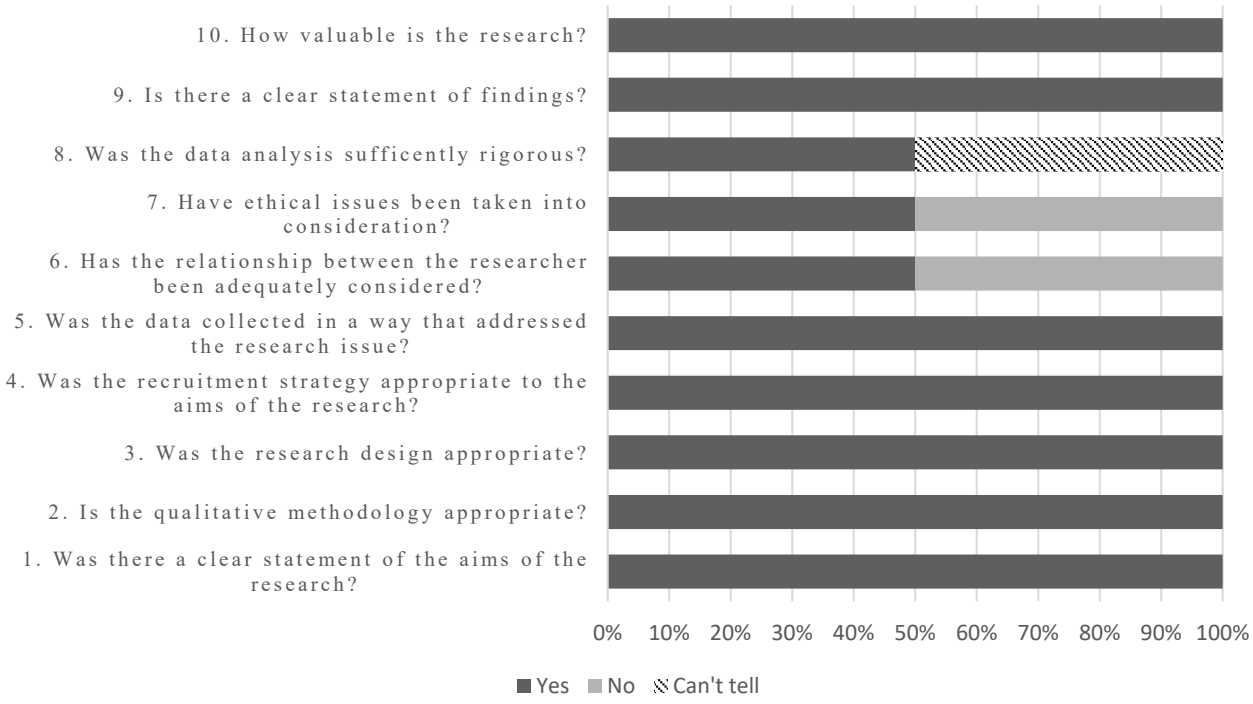
First author (year of publication)	Location	Study design	Setting	Sample size	Patient or healthcare staff	Participant characteristics	PROM used
Allar (2022)	Boston, Massachusetts, USA.	Qualitative interviews	Academic medical centers	24	Healthcare staff	English speaking surgeons using translated PROMs	Not reported
Farina (2022)	Boston, Massachusetts, USA	Qualitative interviews	Cancer treatment and research facility	10	Patients	Spanish-speaking cancer patients	Not reported
Burgess (2022)	Shoalhaven, New South Wales, Australia	Qualitative interviews and focus groups	Community centres and participant homes	29	Patients	Aboriginal and Torres Strait Islander patients with diabetes	PROMIS-29, PAID
Long (2021)	Baltimore, Maryland, USA	Observation and qualitative interviews	Hand and upper extremity clinic	17	Patients	Non-English speaking patients attending clinic	Not reported
Soto-Rey (2018)	Europe	Quantitative survey	Outpatient care centre, dermatologic clinic, and university hospital	495 patients, 28 clinicians	Both	English, French, German, Italian, Polish, Spanish, and Turkish patients attending study clinics; clinicians employed at clinics	MoPat2

Abbreviations *patient-reported outcome measures (PROMs); patient-reported outcomes measurement information system- 29 (PROMIS-29); Problem Areas In Diabetes (PAID); United States of America (USA)*

2.5.3 Assessment of methodological quality

Figure 2 shows the results from the quality appraisal of qualitative studies. Of note, half of the studies did not report sufficient information to determine if data analysis was rigorous (criteria 8) and half of the studies did not clearly describe if ethical issues were addressed (criteria 7), or if the relationship between researchers (criteria 6) was considered.

Figure 2. Methodological quality of included qualitative papers using The Critical Appraisal Skills Programme (CASP) assessment tool.



The results from the quality appraisal of the mixed method study [39] are shown in *Table 4*.

Table 4. Methodological quality of mixed-method papers using Mixed Methods Appraisal Tool (MMAT).

Study	Appraisal	Criteria 1	2	3	4	5	Criteria met	Final score
Soto-Rey (2018)	Mixed method	No	Can't Tell	No	Can't tell	No	0/5	0/5

Note. *Quantitative Criteria: 1) Is the sampling strategy relevant to address the research question? 2) Is the sample representative of the target population? 3) Are the measurements appropriate? 4) Is the risk of nonresponse bias low? 5) Is the statistical analysis appropriate to answer the research question? Qualitative Criteria: 1) Is the qualitative approach appropriate to answer the research question? 2) Are the qualitative data collection methods adequate to address the research question? 3) Are the findings adequately derived from the data? 4) Is the interpretation of results sufficiently substantiated by data? 5) Is there coherence between qualitative data sources, collection, analysis and interpretation? Mixed Methods Criteria: 1) Is there an adequate rationale for using a mixed methods design to address the research question? 2) Are the different components of the study effectively integrated to answer the research question? 3) Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 4) Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5) Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?*

2.5.4 Findings of the review

We identified five strategies to promote PROM completion in CALD and/or Indigenous populations, including one specific strategy reported by Indigenous Peoples, one specific strategy reported by CALD populations, one strategy reported by CALD and Indigenous Peoples, and two strategies from the perspective of healthcare staff about the use of translated PROMs in CALD populations. Notably, few specific strategies addressed how to promote PROM completion in these populations.

2.5.5 Patient-level enablers and strategies.

Theme: Patients had varied levels of digital and health literacy. PROM completion needed to consider varied digital and health literacy in CALD and Indigenous populations.

<u>Indigenous Peoples</u>

An Aboriginal and Torres Strait Islander study participant expressed that PROMs administered verbally would facilitate uptake in Aboriginal and Torres Strait Islander peoples because they *"come from the culture where we're visual, we talk more (Aboriginal and Torres Strait Islander participant)"* [38].

Some Aboriginal and Torres Strait Islander participants reported PROMIS-29 was written at a level above average health literacy and included too much medical jargon, so terminology needed to be simplified and clearer to facilitate completion [38]:

> *"I don't know what diabetes is, you know, in plain English I don't. All the doctor just give me a little tablet and I just took it, and I still don't know what it means. (Aboriginal and Torres Strait Islander participant) [38]*

CALD Populations

One qualitative study among 10 Spanish-speaking cancer patients reported an interest in completing ePROMs if there was a staff member available to help them understand how to use the ePROM platform, which contrasted English-speaking participants who were largely uninterested in ePROMs [36].

ePROMs were accepted by non-English speaking dermatology patients in Europe if the platform was accessible in their home language [39]. For example, administrative and user functions were translated; patients could generate surveys in their preferred language (English, French, German, Italian, Polish, Spanish and Turkish) and respondent burden was reduced by limiting the number of questions patients needed to complete [39]. Older CALD participants were, on average, not willing to complete PROMs in the future and had difficulties using iPads compared with younger CALD participants [39]. In support of this, non-English speaking patients in the USA found ePROMs easier to complete if there were minimal system errors [37].

Theme: Willingness to complete PROMs depended on Indigenous People's understanding of why they were asked to complete PROMs. Ensuring PROMs are culturally appropriate can help Indigenous Peoples understand why PROMs are used. As a strategy to increase PROMs uptake, Aboriginal and Torres Strait Islander participants with diabetes called for community representatives to be included in all stages of research development and conduct to ensure the chosen PROMs aligned with their cultural needs: "the questions need to be looked out from us, like from a cultural way" (Aboriginal and Torres Strait Islander participant) [38]. PROM completion would have been encouraged if there were specific questions about family, culture, and the impact that the Stolen Generations has had on Aboriginal health [38]. Aboriginal and Torres Strait Islander participants believed PROMIS-29 was written with the assumption they had easy access to services, which is not true for

many of them [38]. This finding was not reported by CALD populations in the included studies.

Theme: CALD populations require support to understand and complete PROMs. In several studies, staff, carers, and family tended to help people from a CALD background complete PROMs by translating questions, recording responses, or providing information about what PRO scores meant [35-37]. However, when staff assisted people from a CALD background with completing PROMs through a live phone interpreter, staff did not always accurately read out the PROM questions and responses [37].

2.5.6 Healthcare staff enablers and strategies

Theme: Availability of culturally congruent and linguistically correct PROMs. Notably, no included studies reported the perspectives of healthcare staff that used PROMs with Indigenous Peoples. Both studies that included healthcare staff perspectives explored the use of translated PROMs in CALD populations.

Surgeons felt leadership advocacy and financial resources determined whether using translated PROMs were feasible in clinical care [35]. Surgeons reflected that access to culturally congruent and linguistically correct PROMs were important so that no matter the person's culture or language, questions were interpreted in the same way and meaningful to the patient's lived experience: *"Something just transcribed from English to another language does not necessarily equate to what the intention of the questionnaire was"* [35].

Theme: PROMs should add value to existing clinical practice. Both studies that reported on the perspectives of healthcare staff highlighted that the effort to use translated PROMs should coincide with the added value to biomedical evaluations [35, 39]. One surgeon wanted to see the benefit of PROM use more clearly to encourage them to "buy in" to using translated PROMs: *"it's getting patients to buy in, but it's also getting us docs to buy in"* [35].

Theme: ePROMs can promote use of translated PROMs in existing workflows. As electronic medical records (EMR) were in English, the ability to embed translated PROMs into the EMR was important for some healthcare staff. For surgeons, this was because it would improve accessibility of PROM data, encourage use of translated PROMs, and reduce need for interpreters [35]. Dermatologists in Europe reported ePROMs were highly acceptable as the system reduced resources required to obtain and administer translated PROMs in clinics and data from multiple surveys was safely stored in a central system [39].

Based on our findings, strategies to promote PROM completion by CALD and Indigenous Peoples are reported in *Table 5*.

Table 5: Summary of recommendations to support and increase PROM completion, by CALD and Indigenous populations, based on evidence from included studies.

Stage	Recommendations
During PROM development for CALD and Indigenous populations	• Consider the needs of individual populations and whether cultural and linguistic adaptations are required, rather than just language translation [34]. • PROMs should be developed free from medical jargon, suitable for patients with low health literacy[37]. • PROMs should be co-designed with communities to ensure questions align with culture and lived experiences[37]. • Increase financial resources and leadership support to embed translated PROMs in clinical workflows[34, 38].
During ePROM system development	• Ensure ePROM systems are accessibly designed prior to completion (e.g., minimal system errors, user friendly for patients, embedded in EMR for healthcare staff, result outputs for translated PROMs in English).
During patient communication about PROM completion (explaining purpose, explaining importance).	• Offer patients different modes of PROM completion based on personal preference. Consider developing PROMs that can be completed verbally[37]. • Healthcare staff should explain to family and carers the importance of reading PROM questions and responses *in verbatim* to patients [34-36]. • The purpose and importance of PROMs and the meaning of questions should be communicated to patients prior to completion (e.g., video resources, via healthcare staff, community members, etc.)[37].
After PROM completion	• Healthcare staff should help patients understand how PROM data relates to health-related quality of life, therapeutic options, or when compared to average scores for the relevant patient cohorts.

2.6 Discussion

This study synthesises strategies of PROM completion by CALD and Indigenous Peoples and their healthcare teams. The main findings were 1) offering different modes of completion could facilitate PROM completion by accommodating varied health and digital literacy levels, 2) patients required assistance to understand and complete PROMs, and 3) surgeons believed culturally and linguistically appropriate translations of PROMs were important but difficult to obtain and embed in clinical workflows. These findings are consistent with other systematic reviews reporting the barriers and enablers for PROM implementation in English-speaking populations [40].

Some unique findings, specific to Indigenous Peoples were 1) the content of PROMIS-29 and PAID was not acceptable to Aboriginal and Torres Strait Islander Peoples who speak Australian Aboriginal English (AAE) rather than Standard English; 2) verbal completion may be a culturally appropriate mode of completion for Aboriginal and Torres Strait Islander Peoples. Further research is required to determine how these strategies could be implemented with other Indigenous populations, and whether they could be adopted by CALD populations.

The Agency of Clinical Innovation (Sydney, Australia), our project partner, collect ePROMs in 11 community languages in New South Wales (NSW) using a digital platform-the Health Outcomes and Patient Experience (HOPE). At the time of publication, over 108,000 PROMs have been collected using HOPE, which has been translated into 10 community languages other than English. Given the success of this large-scale digitally enabled collection of PROMs, the blueprint for this program has been adopted by other Australian states. With this in mind, we consider how enablers reported in this review can be

feasibly scaled into large-scale PROM initiatives for CALD and Indigenous populations globally.

Offering PROMs in a range of community languages may overcome some reported challenges such as circumnavigating language and cultural barriers during clinical encounters (e.g., assessing pain), especially if an interpreter is unavailable. Reflecting the importance of this, HOPE was co-designed with patients and carers.

To be meaningful to patients and useful in clinical practice, evidence suggests PROMs should not only be translated but also culturally and linguistically adapted to ensure acceptability and appropriateness amongst CALD and Indigenous Peoples and healthcare staff [39], and applicable in clinical care settings. Across cultural groups in this study, there was mixed evidence about the importance of culturally and linguistically adapted PROMs. For Aboriginal and Torres Strait Islander peoples in this study, PROMIS-29 did not align with their lived experience, values, and daily priorities [38]. On the contrary, one study set in an European dermatology clinic did not report evidence their ePROM system was culturally adapted, appropriate or if there was training provided to patients to complete ePROMs [39]. Nevertheless, people from a CALD background found ePROMs easy to use [39]. Further, evidence is required to elucidate if translations are culturally appropriate or if cultural adaption is required to promote the acceptability of PROMs within a European context and other CALD populations.

Our review reported that when patients had assistance to complete PROMs, questions and responses were not always read precisely [37]. This emphasises the importance of reading PROMs *in verbatim*, to minimise interpretation errors, which can contribute to inaccurate responses and therefore misinformed clinical care. Importantly, for CALD and Indigenous Peoples to self-complete PROMs, administrative instructions should also be

translated into their preferred language, which facilitated the reported success of one included study in an European dermatology setting [39] and is also a feature of HOPE. Integration of translated PROM data with patients' EMR would facilitate PROM use by healthcare staff and enable linkage of PROs to clinical events to facilitate timely care [43], a feature available in HOPE.

There may also be cultural barriers to PROM completion that can be overcome with novel developments in PROM administration, such as verbal completion in a patient's preferred language. For example, 'yarning' builds a culturally safe environment for Aboriginal and Torres Strait Islander peoples by giving the community a space to talk, share, educate and build relationships [41, 42]. Yarning can facilitate culturally competent research and healthcare by emphasising two-way communication between health practitioners (or researchers) and participants [41, 42]. PROMs could be collected while Aboriginal and Torres Strait Islander Peoples yarn, fostering trust between healthcare staff and patients [38].

Implications on practice, policy, and future research

Findings from this review have implications for practice and policy as several recommendations to promoting the completion of PROMs by CALD and Indigenous Peoples have been made. In future research, in partnership with NSW Health, we will explore the gap in documented knowledge about factors that determine the acceptability and suitability of PROMs to diverse cultural and linguistic populations [44]. By addressing these challenges, we can move towards a more equitable healthcare system that respects and responds to the unique needs of all patients, regardless of cultural or language background.

Limitations

Notably, few studies met the eligibility criteria for this review. This was primarily because papers: 1) mentioned CALD and/or Indigenous terms in the title or abstract, but not within the study design; and/or 2) did not use PROMs as their intervention 3) reported only barriers and not strategies. The quality of the evidence using the MMAT appraisal tool was low, highlighting the need for high-quality, robust evidence of specific strategies of PROM completion in CALD and Indigenous populations. Incongruent definitions or terms to describe CALD and Indigenous populations were used in the literature. To mitigate this, we ensured our search strategy was comprehensive and incorporated terms used globally to describe these populations. The search was restricted to published scientific literature; it may be possible that relevant learnings from grey literature were missed.

Conclusion

Some PROMs do not reflect the priorities and lived experiences of CALD or Indigenous Peoples, leading to poor uptake. Consultation with people from a CALD background and Indigenous Peoples during PROM development and implementation could improve completion ensuring the content, mode of administration and implementation approaches were culturally appropriate and acceptable. Further, to successfully promote the completion of translated PROMs within chronic care settings, adequate training, planning, resourcing, and financial support are required for healthcare teams. Improving the completion rates of PROMs by CALD and Indigenous peoples will contribute to a more comprehensive and equitable assessment of patient needs, better-informed clinical decisions, and a significant enhancement in these individuals' overall quality of life.

Abbreviations

CALD: culturally and linguistically diverse; PRO: patient-reported outcome; PROM: patient-reported outcome measures; HRQL: health-related quality of life; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; CASP: Critical Appraisal Skills Programme; MMAT: Mixed-methods Appraisal Tool; PAID: Problem Areas in Diabetes; PruNet: European Network on Assessment of Severity and Burden of Pruritus

Author contributions

JN designed this review and protocol, developed the search strategy, screened all papers across all stages, extracted the data, conducted data analysis and synthesis, and developed the main draft of the manuscript. BK contributed to formulating the search strategy, conducted 20% of title and abstract screening and screened all full-text papers and conducted the quality appraisal with JN. CR contributed to the conception and design of the project, results interpretation, writing of the manuscript, and project supervision; had full access to the data in the study; and takes responsibility for the integrity of the data and accuracy of the data analysis. RLM contributed to design of the review, clarification of eligibility criteria, data extraction and synthesis methods (e.g. in supervision meetings and team presentations). RMB, BR, MF, JFL, KS and GH contributed to study design, read, revised and approved the final manuscript.

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3. Symptom monitoring in dialysis

The previous chapter bridged a gap in our understanding of how to promote PROM completion by people from CALD backgrounds and Indigenous Peoples. Chapter 3 leverages the Symptom Monitoring with Feedback Trial (SWIFT) to address thesis Aims 3 and 4. This chapter presents a qualitative study that explored usual care for symptom monitoring for patients with kidney failure. In this clinical context, patient-reported outcome measures (PROMs) have an important role in informing the clinical care of these patients who experience high symptom burden and poor health-related quality of life (HRQL).

In 2022 in Australia, 264,000 people were diagnosed and treated for kidney failure [1]. Kidney failure contributed to 12% of all deaths in Australia in 2021 [2], with patients living an average of three to five years post-diagnosis [3]. The five-year survival rate is around 50%- lower than all cancers combined [4]. Patients with kidney failure often report that HRQL and symptom burden are more important to them than clinical outcomes such as survival. Thus, the shift to person-centred care is timely to address the priorities of patients with kidney failure [5].

There are three main treatment approaches for kidney failure: kidney transplant, dialysis and conservative care. If patients are eligible and there is availability, kidney transplant is offered to replace kidneys. To date, 13,648 Australians have received a kidney transplant, of which 1,088 Australians received a kidney transplant in 2023 [6]. However, waiting periods are long (median wait time 2.2 years) [7], and patients continue to live with poor quality of life during this time.

Home, hospital or satellite dialysis to replace the function of the kidney can be used to prolong a patient's life whilst they wait for a transplant, or if they do not meet eligibility for transplant [2]. Haemodialysis involves artificially removing waste and excess water from

blood and maintaining safe electrolyte levels. In 2023, 15,623 Australians were treated using haemodialysis [33]. Haemodialysis has a significant symptom burden ranging from physical discomforts such as fatigue and dry skin to psychological distress such as anxiety and depression [8] and can be time-consuming (four to five hours, three times per week) [2].

Kidney replacement and haemodialysis are treatment approaches associated with a medical model of care where biomedical markers (blood test results and fluid assessments) are used to 'cure' kidney failure by managing blood pressure, blood water volume and electrolytes. Resultingly, there has been a historical lack of attention given to symptoms of kidney failure and/or haemodialysis that can prevent patients from living their lives to the fullest.

Conservative care is a more recent approach that recognises that haemodialysis or transplant does not benefit every patient, especially if patients are older, have multimorbidity, significant deterioration in functional status and increased palliative care needs. Conservative care means patients receive the same treatment without kidney transplant or dialysis, to control symptoms and improve quality of life through reduced hospitalisations and symptom relief in the last year of their life [3]. Aligning with the goals of person-centred models of care, conservative care for patients with kidney failure prioritises shared decision-making, minimising patient suffering, and providing ongoing supportive care to alleviate symptom burden [9].

The Symptom Monitoring wIth Feedback Trial (SWIFT) is Australia's first registry-based cluster randomised trial of self-reported symptoms [10]. SWIFT aims to explore the implementation of ePROMs in routine care settings in a population of haemodialysis patients. In the control arm, patients receive 'usual care' as per existing clinic workflow and complete PROMs (EQ-5D-5L and SONG HD Fatigue) every six months for a year. In the intervention

arm, patients complete PROMs for a year (IPOS Renal every three months and EQ-5D-5L and SONG HD Fatigue every six months). The completed IPOS Renal is sent to the dialysis nurses, and the patient's nephrologist is asked to follow up symptoms at the next clinical encounter. SWIFT offers ePROMs in eight community languages including English.

SWIFT was developed to address the problem that standard dialysis care does not typically focus on quality of life or alleviating symptom burden but on managing blood concentrations of urea, potassium and phosphate. Therefore, clinicians have missed opportunities to intervene and address symptoms to improve a patient's HRQL.

Symptom monitoring is reported to improve symptoms and survival [4], aligning patient and clinician priorities. A systematic review of the routine use of PROMs in trials found using PROMs increased the frequency of discussion of PROs during clinical encounters and, in some cases, improved symptom control, supportive care measures and patient satisfaction [11]. However, clearer guidelines for clinicians to guide how they respond to patient concerns are needed.

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Exploring usual care for symptom monitoring in dialysis: A qualitative study alongside the Symptom Monitoring with Feedback Trial (SWIFT)

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3.1 Abstract

Purpose

Haemodialysis is a life-sustaining treatment for kidney failure but is associated with significant symptom burden. This qualitative study aims to explore standard care practices for assessing, monitoring, and managing kidney failure symptoms in haemodialysis patients across Australia from the perspective of nephrologists, palliative care physicians and renal nurses.

Methods

Clinicians participating in the Symptom monitoring With Feedback Trial (SWIFT) were invited to participate in a one-off interview *via* videoconference, either before SWIFT was commenced in their unit, or following the end of the study. Interpretive description, an inductive analytic approach, was used to understand and describe the clinical approach to symptom monitoring.

Results

Thirty-one clinicians (14 nephrologists, 2 palliative care physicians, 15 nurses) were interviewed across 13 kidney treatment centers in three Australian states. Three main themes were identified: 1) preferences for open-ended questions to capture and monitor symptoms rather than standardised questionnaires; 2) symptom monitoring perceived as futile for some clinicians managing patients with kidney failure; 3) individualising symptom assessment and monitoring practices for Indigenous Peoples, people from culturally and linguistically diverse backgrounds and frail patient populations. Findings underscore less formalised symptom assessment and monitoring practices, and a greater focus on patients' quality of life are needed for patients on haemodialysis.

3.2 Introduction

It is estimated up to 1.7 million Australians show biomedical signs of kidney disease [1] with 264,000 diagnosed and treated for this condition in 2022 [2]. Haemodialysis is most commonly to manage kidney failure [3], with 15,623 Australians receiving this treatment in 2024 [4].

Life on haemodialysis is associated with significant symptom burden despite being life-sustaining. Common symptoms, including physical discomfort (e.g., fatigue and dry skin), to psychological distress (e.g., anxiety and depression), can severely impact patients' quality of life [5]. Despite their high prevalence, symptoms are often under-recognised and under-treated [6, 7]. Symptom management for patients on haemodialysis can be more challenging than other conditions because symptoms can be non-specific to kidney failure (e.g. nausea) and the underlying mechanisms may be inadequately understood.

The Symptom monitoring WIth Feedback Trial (SWIFT) is the first Australian registry-based cluster randomised trial [8]. The SWIFT aims to assess the clinical and cost-effectiveness of using the Integrated Palliative care Outcome Scale (IPOS) Renal measure for symptom monitoring completed electronically every three months by adults on haemodialysis. The IPOS Renal is a patient-reported outcome measure (PROM) that allows patients to self-report their symptom burden, treatment side effects and health-related quality of life. By systematically capturing these experiences using patient-reported outcome measures (PROMs), clinicians can identify symptoms earlier, helping them act proactively with timely and targeted interventions because they have a better understanding of their patients' experiences to tailor treatment plans and improve overall care.

SWIFT is offered in eight community languages: English, Arabic, Vietnamese, Korean, Greek, Italian, Traditional Chinese, and Simplified Chinese to reflect Australia's

diverse multicultural community. Published findings from the SWIFT pilot [9] and pre-trial qualitative study [10] indicated the acceptability of using the IPOS Renal to support symptom monitoring in adults managed with haemodialysis. To determine whether the SWIFT intervention will make a difference in clinical management and, ultimately, patients' quality of life, we need to understand how symptoms are assessed and managed in routine clinical care in the absence of the trial intervention. This qualitative study (herein SWIFT sub-study) aims to explore clinician and renal unit standard care practices for assessing, monitoring, and managing kidney failure symptoms in haemodialysis patients, across Australia.

3.3 Methods

Ethics approval for the SWIFT main trial and sub-study were obtained from the Human Research Ethics Committees (HREC/18/CALHN/481; HREC/MML/54599). Findings have been reported according to the Standards for Reporting Qualitative Research (SRQR) [11] (See Supplementary File 1).

3.3.1 Study Design

Clinicians participating in SWIFT were emailed an invitation to participate in the sub-study - a single one-on-one interview with study researchers over videoconference using Zoom.

3.3.2 Eligibility Criteria

All clinicians (nephrologists, nurses and relevant other staff such as palliative care physicians) at sites registered in SWIFT, were eligible and invited to participate in the qualitative sub-study either before or after 12-month data collection for the main trial.

3.3.3 Recruitment and Consent

Study researchers emailed eligible clinicians an invitation and participant information sheet (see Supplementary File 2). Written or verbal informed consent was obtained before interviews commenced. Recruitment ended when no new data or themes emerged from participant interviews (i.e. data saturation), which we defined as the stage where all concepts related to the aim could be described in detail and no further interviews provided additional information [12].

3.3.4 Data Collection

Three researchers (MA [nephrologist], SH, JN [research assistants]) with qualitative research and/or clinical expertise conducted semi-structured interviews between September 2020 and September 2024 over the course of the SWIFT trial. The interviews were scheduled according to participant availability, conducted via Zoom, audio-recorded, and transcribed verbatim by the researchers. An interview topic guide covered: current use of symptom assessment measures; symptom assessment practices for specific populations (e.g. culturally and linguistically diverse [CALD], frail); management of high-burden symptoms; and considerations to improve symptom assessment and management. The interview topic guide is available in Supplementary File 3.

3.3.5 Data Analysis

An interpretive description methodology was selected to guide the analysis because symptom monitoring practices in haemodialysis centres are complex, contextually embedded research with clinical applications [13]. Interpretive description is a qualitative research approach used to identify and apply aggregated knowledge about clinical practice that can be examined by

identifying themes among participants, whilst also identifying variations between participants [14].

Data analysis occurred in parallel with data collection by a core team (JN, MA, RLM) comprising clinical, clinical trials research, and qualitative research expertise. Braun and Clarke's reflexive thematic analysis approach with an inductive approach was followed, which included six phases: analysis, coding, generating initial themes, developing and reviewing themes, and writing up [15, 16]. Transcripts were reviewed multiple times to ensure familiarity with the data. Then, line by line, JN coded small portions of participant responses using NVivo 12 software (QSR International) [17] for data management. The core team [JN, RLM, MA] engaged in an iterative process to build themes by grouping codes of similar meaning. The wider project team which included individuals from various clinical and research backgrounds refined and finalised these themes. Triangulation of all perspectives from the research term ensured the full range and depth of data were explored [18]. Findings were synthesised into themes and sub-themes. Sub-themes were reported to show how different aspects of the main theme were related.

3.3.6 Reflexivity

JN, a junior qualitative researcher from a non-clinical background considered how coming from a CALD background and their experience as a consumer and youth representative in healthcare services had enriched their understanding of the healthcare landscape, particularly in advocating for diverse community needs. They acknowledged their non-clinical background and experiences might have introduced certain biases into the research such as a heightened sensitivity to issues faced by CALD communities, which might lead to an overemphasis on these aspects in their analysis. These biases also bring valuable insights, particularly in understanding the patient and community perspectives that are often

underrepresented in clinical research. MA, reflected on his experience as a nephrologist providing symptom management care to kidney patients, and how the health services he had worked in supported (or did not support) this.

3.4 Results

Thirty-one English-speaking participants including 14 nephrologists, 2 palliative care clinicians and 15 renal nurses, were interviewed across 13 sites in three Australian states. Interviews lasted up to an hour. See Table 1 for clinic characteristics and Table 2 for participant professions. Participant quotes were reported using pseudonyms as a means to humanise the data [19] and reported in Table 3. Figure 2 is a visual representation of the themes, sub-themes and minor themes arising from interviews.

Table 1. Site characteristics (N=13)

Characteristic	**n (%)**
Australian State	
New South Wales	*8 (62)*
Queensland	*3 (23)*
Victoria	*2 (15)*
Health sector	
Public practice	9 (70)
Private practice	4 (31)
Location	
Metropolitan	*6 (46)*
Rural	*5 (54)*

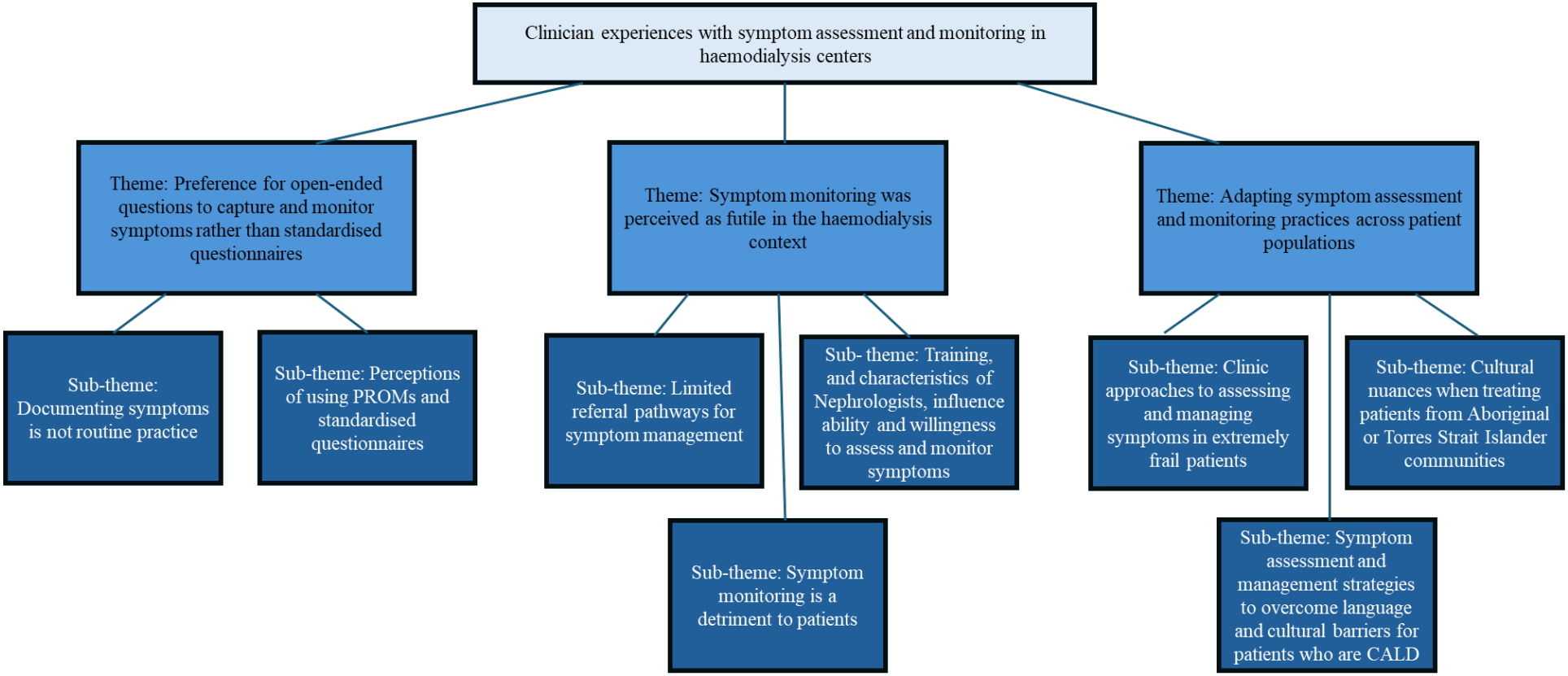
Table 2. Participant characteristics (N=31)

Clinician type	***n (%)***
Nephrologist	*14 (44)*
Palliative Care Physician	*2 (6)*
Nurse Unit Manager	*8 (25)*
Clinical Nurse Consultant	*4 (18)*
Renal Supportive Care nurse	*1 (3)*
Clinical Trial Coordinator	*2 (6)*

Table 3. Participant pseudonyms for reporting

Pseudonym	Participant Description
Dean	Nephrologist, male, regional Queensland
Bardu	Nephrologist, male, rural New South Wales
Richard	Nephrologist, male, metropolitan New South Wales
Angus	Nephrologist, male, metropolitan New South Wales
Victoria	Nephrologist, female, metropolitan New South Wales
Murray	Clinical Nurse Consultant, male, rural Victoria
Gary	Nephrologist, male, metropolitan New South Wales
Gabriella	Nurse Unit Manager, female, Regional New South Wales
Alice	Clinical Nurse Consultant, female, metropolitan New South Wales
Tim	Nephrologist, male, metropolitan New South Wales
Linda	Nephrologist, female, metropolitan New South Wales
Vivian	Palliative Care Physician, female, regional New South Wales
Brittany	Clinical Trials Nurse, female, regional Victoria
Samantha	Nurse Unit Manager, female, regional New South Wales
Gemma	Palliative Care Physician, female, regional-metropolitan New South Wales
Lucas	Nephrologist, male, regional-metropolitan New South Wales
Lucy	Clinical Nurse Consultant, female, metropolitan New South Wales
Daniel	Nephrologist, male, metropolitan New South Wales
Elijah	Nephrologist, male, regional-metropolitan New South Wales
Bao	Nephrologist, male, metropolitan New South Wales
Jessica	Palliative Care Physician, female, metropolitan New South Wales
Martina	Nurse Unit Manager, female, metropolitan New South Wales

Figure 2. Visual representation of themes.



Note. *Clinician experiences with symptom assessment and monitoring in Australian haemodialysis centers led to the development of three main themes. Each theme also included sub-themes and minor themes exploring varied perspectives within the theme. Abbreviations: patient-reported outcome measures (PROMs); culturally and linguistically diverse (CALD).*

The main symptoms causing the most significant burden for patients were *"…fatigue, pruritus, chronic pain, loss of appetite, altered taste, and quality of life overall"* (Angus) and clinicians believed that these symptoms "*were mainly overcome by people who have a positive attitude"* (Richard).

Clinicians reported haemodialysis patients had other chronic conditions that needed to be considered when assessing and managing symptom burden related to haemodialysis: "*I think patients who are on dialysis also have lots of other medical conditions. They always have something or the other going on*" (Dean), further complicating assessment and management of symptoms where each patient had a *"…unique personality, unique perception of symptoms, unique thinking, unique response"* (Bardu).

Clinicians reflected that caring for patients with kidney failure was not about curing the patient or extending their life, but more about improving the quality of their life by alleviating some symptoms: *"I think that dialysis is all about affording quality of life as much or more so than duration of life, and so should be a primary focus of ours"* (Gary).

Nurses were the first point of contact for patients when they visited the haemodialysis centre, and patients, where possible, were allocated one nurse who would be with them long-term. Continuity of care was important to build rapport and understand a patient's day-to-day life: *"…one has to understand that dialysis patients on dialysis live their lives with the staff on a recurrent basis. So we become part of their lives in a way and there's a whole lot of things going on in a person's life and they all spill over into the dialysis unit"* (Bardu) and to monitor changes to their symptoms over time: *"…are cramps normal or not? There are a lot of little things which you figure out if you have known the patient for many months or years"* (Bardu).

Generally, there were no criteria applied by clinicians to determine which patients would be asked questions (either verbally or using PROMs) about their symptom burden. However, only patients who reported concerning symptoms had them recorded in electronic medical records to be actioned by multidisciplinary care teams.

Clinicians reported not assessing or monitoring symptoms for many reasons, such as: there was no referral system in place if symptoms were identified; patients reported symptoms that were not dialysis specific; the patient was frail, and clinicians were unsure about the value of managing symptoms due to the presence of multiple health conditions, the patient's age, and the progression of kidney failure.

Theme: Preference for open-ended questions to capture and monitor symptoms rather than standardised questionnaires

To differing degrees, all clinicians conducted informal symptom assessment and monitoring at the start of the consultation by asking verbal, open-ended questions such as *"...how've you been, any issues you want to raise, any concerns?"* (Bardu) to allow patients to self-report any burdensome symptoms they wished to address.

Clinicians were able to unpack symptoms by asking probing questions *"...[we ask]' why is that?' Then you would start investigating and asking more questions, trying to get a bit more of a history"* (Gabriella). Understanding a patient's history, for example, involved probing for patterns of eating behaviour to determine if symptoms such as fluid retention were because of dialysis titrations or due to changed patterns of dietary potassium or sodium intake. Nephrologists, in particular, used blood tests and fluid assessment results to guide the verbal, open-ended symptom questions they asked patients: "…*monthly bloods should also trigger questions- if phosphate's low it's about itch, if haemoglobin is low it's about energy and quality of life"* (Bardu).

Clinicians reflected an informal approach helped them probe 'why' to understand symptom severity and its impact on a patient's daily life. Coincidingly, this promoted clinician-patient rapport that helped patients feel more comfortable and engaged during clinical encounters: *"…asking questions in a… non-threatening fashion… less organised fashion with patients, they're more willing to engage and discuss"* (Tim).

Clinicians described that patients would volunteer information without prompting if they had a burdensome symptom: *"you don't have to ask questions, they can't help themselves but tell you"* (Gabriella). In contrast, some patients did not report symptoms because *"…unless you ask about symptoms, they'll just assume it's part of dialysis and won't say anything"* (Lucy).

Verbal, general questions about a patient's daily priorities and desired outcomes of treatment allowed clinical encounters to focus on building a patient's capacity to live life to the fullest around scheduled haemodialysis. Nurses similarly shared that as part of their standard of care, they developed a rapport with patients, allowing them to ask open-ended questions about a patient's socioeconomic context and dietary behaviours to allow referral to allied health (e.g. social worker) and support services if needed so that patients could manage their day-to-day activities and responsibilities (e.g. looking after children, managing finances): *"…[for example] 'this patient is a bit tricky socially, with housing problems', say, or some other problems [like] lack of support, then we can get the social worker. If they think there's some dietary issue then we have a dietitian"* (Bardu).

Sub-theme: Documenting symptoms is not routine practice. Patient-reported symptoms were not always documented in electronic medical records or patient notes because it was not always standard practice or there was too much information to record: "*…not everything gets documented and there is information overload obviously. Even if*

everything gets documented we can't go through that" (Bardu). Consequently, other staff were not always aware of a patient's history or current symptoms, such as if *"…the ward is busy [or] a junior staff doesn't ask a question. A senior staff might be more alert to the potential issue"* (Martina), reflecting the benefit of experience to pick-up symptoms using verbal, unstructured questions.

Sub-theme: Perceptions of using patient-reported outcome measures (PROMs) and standardized questionnaires. Few clinicians had experience using PROMs and standardised questionnaires to screen for dialysis-specific symptoms. Unlike asking verbal, open-ended questions, understanding a patients' goals was deemed impossible to capture using PROMs. For example, PROMs were not perceived to capture the social, psychological and personal aspects of a patients' life; to provide positive outcomes for patients, *"you've got to know the story"* (Linda).

Clinicians who used PROMs noted that quality of life data was not standalone information that gave a full picture of a patients' symptoms- it needed interpretation in the context of a patients' life. PROMs should be looked at in combination with blood tests and fluid examinations, for example: "*I can live with it now, it doesn't impair my quality of life' is more valuable whether or not it's the same in the IPOS score"* (Vivian). PROMs enabled focused and *"…a structured way to ask patients questions about how they're feeling and the effects of treatment and other issues"* (Brittany). Further, self-completing PROMs gave patients time to reflect on their health and advocate for what mattered most to them: "*…having the time to fill out the survey themselves, I think gives…[patients] a voice for their situation that they might not otherwise have"* (Daniel).

Clinicians could access data to quickly glance over scores before clinical encounters, especially when first meeting a new patient. Some clinicians reflected that participating in

SWIFT and using PROMs could help systematically document symptoms without relying on memory or losing key information in patient notes: *"…we're just relying on individuals remembering things and that doesn't translate well when you've got lots of staff turnover all the time"* (Tim).

The IPOS Renal was considered a fit-for-purpose tool by clinicians who reported using it. However, one nephrologist reflected that the symptoms did not follow a progression to facilitate consultations, as questions were not grouped logically:*"… so what I would do is ask the questions in a way that is logical to my diagnostic reasoning…just trying to group things together in a more clinically logical way, in particular grouping gastrointestinal side effects: dry mouth, low appetite, nausea, constipation, diarrhoea"* (Daniel). One palliative care physician described IPOS-renal as being useful to provide a 'snapshot' of patient symptoms as it was validated as a point-in-time tool but was unsure if it could be used to track symptom progression over time (longitudinal use): *"patients can't necessarily go back and look at what they scored three months ago and then balance it against that. It's not validated for that"* (Gemma).

Nephrologists reasoned that individual clinic consultations were too short to refer to or act on PROM data, given the competing demands of assessing and discussing blood test results, writing referrals, and outlining patient treatment programs: *"it's time management, time constraints and trying to prioritise things. You know we all get tied up with our day-to-day dealings of things"* (Alice) with the rationale, *"there is only 20 minutes for each patient. There really is not much time, although we would love to [use PROMs]"* (Elijah). Being time deficient meant nephrologists did not ask about all symptoms and preferred using clinical judgement or waiting for the patient to bring up burdensome symptoms to save time and money: *"you see a patient and you generate a certain income…then if you have this long*

assessment tool where clearly you're going to be exceeding the time that you can spend with your patients—and after all this patient comes every three months" (Bao).

Current workflows were also not established to store paper-based survey data or to integrate PROMs data into electronic systems for multidisciplinary care teams to review data about a patients' symptoms over time: "…*if we can utilise REDCap that will be able to see trends in IPOS will be really useful, but it's not what we've done up to now. Up to now, it's been more useful on a snapshot basis of what the symptom burden is"* (Jessica).

Theme: Symptom monitoring was perceived as futile in the haemodialysis context

Some clinicians shared they felt symptom monitoring was futile when considering the complexity of care for haemodialysis patients and the limitations of clinic resources such as staff and referral options. In their experience, patients often reported symptom burden unspecific to haemodialysis (e.g. generalised pain and fatigue) or because of ageing and, therefore, could not be managed by the clinician*: "most of the time it's just degeneration, so you can't do anything about it"*(Martina) and "*I think symptom management is good, however, when the patient is getting older and frailer, there is a limitation to improving the symptom burden. So that is my frustration, I don't know the best way to deal with it"* (Samantha).

Some clinicians reported symptoms of kidney failure were progressive and unlikely to improve. Instead, patients developed tolerance for their symptoms and, therefore, some clinicians perceived it was futile to assess and manage patient symptoms: *"there is nothing we can do other than medication treatment. There is not much significant improvement. So the dialysis patients do have a very high tolerance with the symptom burden because they're used it"* (Samantha).

Symptom assessment also relied on patients admitting they had symptom burden affecting their quality of life; if symptoms were not reported, clinicians felt there was no point in collecting symptom information. Clinicians reported that male patients typically were less likely to report symptoms than female patients: *"…obviously there are some particular patients—particularly the male patients: 'you know, look I'm doing fine, I don't have any problem.' Then the nurses would tell us: look this patient is slowly declining"* (Bardu). On the other hand, clinicians who believed referral would alleviate some symptom burden, referred patients to allied health. However, symptom monitoring was perceived as futile if the patient did not take up referrals or adhere to treatment (e.g. prescribed diet in general or around holidays).

Nephrologists focused on blood and fluid testing to monitor patients' responses to haemodialysis, rather than symptom management: "*I have to admit that symptom management is often not addressed in Nephrology…we focus on access and biochemical markers*" (Victoria). Pathology tests were perceived to be a measurable way to identify which symptoms were dialysis-specific and could be acted upon within the haemodialysis centre, and the symptoms that needed to be referred to other specialities to manage. Biochemical markers were preferred because "…*dialysis is a regular treatment; the symptom is often related to the result. For example, [patients] have itchiness, which means high phosphate level. Or anaemia, you see that the haemoglobin level is low. They often experience lethargy, fatigue. So, in this way, you can kind of find that the symptom is related to the blood result. And the doctor is there to pick up and manage it*" (Samantha).

Sub-theme: Limited referral pathways for symptom management. Some clinicians were sceptical of the benefit of symptom monitoring if there were no clear management pathways available to reduce or alleviate symptoms. The rationale was that

collecting this data was *"…actually useless if nobody does anything about the symptoms… you're just recording data and no one helps the patient".* Other clinicians resonated with this, acknowledging they did not have the clinic infrastructure, staff and allied health support available to action the symptoms reported by patients: *"…we don't have regular access [to allied health] because we are not well funded"* (Victoria). Therefore, if symptoms were not a result of haemodialysis or kidney-related, it was perceived as not the responsibility of the nephrologist to manage these symptoms but rather the purpose of referring to allied health staff. In the absence of referral options, some clinics provided patients with their blood test results in a lay summary with some advice from nurses about diet management.

One nephrologist explained that given they were practising in a rural haemodialysis centre, they did not have the support system to assess and then manage complex symptoms presented by patients: *"…in my area, in a regional centre in Queensland, you don't have other people to refer to. You're it"* (Dean).

Sub-theme: Symptom monitoring is a detriment to patients. One nephrologist described the importance of not focusing on the 'burden' of kidney failure because, in their experience, patients adopted a 'sick role' and lost sight of their life goals and reasons for needing dialysis (e.g. ability to look after their child, going on holidays with their families, working): *"I don't let the patients adopt the sick role… If the patient asked me, 'How long am I going to live?' I say, 'I don't know, but while you're alive we're going to enjoy it"* (Linda). Symptom assessment and monitoring were perceived as a detriment to their patients, preventing them from living life to the fullest and taking ownership of their condition and health status. Instead, adhering to haemodialysis and being on dialysis for additional hours throughout the week was perceived to be more important than addressing individual symptom burden in helping patients live well with kidney failure.

Sub-theme theme: Training, and characteristics of nephrologists, influence ability and willingness to assess and monitor symptoms. One nephrologist reflected on various factors that specifically may influence a Nephrologists' ability and willingness to monitor symptoms of haemodialysis patients. First, over time therapeutic options and knowledge have improved, offering patients hope in the form of drugs to manage symptoms*: "I think we've come a long way; we've got clearer drugs that have got a defined mode of action"* (Richard). Speciality training in Nephrology now incorporates a larger focus on symptom monitoring, increasing Nephrologists' confidence in assessing and monitoring symptoms *"…you'd have to go to a special clinic to have someone talk to you about your symptoms, and I think now most nephrology trainees who come into training would have a much more comfortable… a higher level of comfort managing symptoms themselves without referring to another service"* (Richard). They also reflected on the importance of being guided by a patients' decision-making about their care *"…there's a tension between not wanting to harm, non-maleficence, and wanting to respect patients' autonomy"* (Richard), which arose when deciding on whether dialysis or conservative care was more appropriate to manage symptom burden and quality of life for a patient. The nephrologist also reflected on variations in workload across their career that may constrain the ability to assess and monitor symptoms: *"there is a sort of stage of career effect I think as well… the volume load of your patients builds up over time…you do get less time with your patients, and you become very familiar with them as well, so you may not make those same standardised or check-list approaches to symptoms"* (Richard).

Theme: Adapting symptom assessment and monitoring practices across patient populations

Clinicians reported models of care for patients from CALD backgrounds, Indigenous Peoples and frail patients. The strategies to engage these populations could be applied to symptom

assessment and monitoring. Most clinicians reported that their patient population were not CALD or Aboriginal and Torres Strait Islander due to their haemodialysis centre sitting within a homogenous English-speaking, non-CALD or Indigenous community.

Sub-theme: Cultural nuances when treating patients from Aboriginal or Torres Strait Islander communities. Notably, no clinicians identified themselves as Aboriginal or Torres Strait Islanders, and only some clinicians reported treating Aboriginal or Torres Strait Islander Peoples. Strategies reported to help clinicians to care for Aboriginal and Torres Strait Islander communities included cultural training and Aboriginal Liaison Officers to first meet the patient when they were admitted for haemodialysis: *"if a patient presents the dialysis and we admit them and they identify as being our Aboriginal Torres Strait Islanders, then an alert will go to the Aboriginal health unit… they touch base with [patients] once a week or more frequently"* (Murray). Aboriginal Liaison Officers helped patients with health literacy and understanding haemodialysis. It was also important to offer patients male and female officers in keeping with cultural norms: *"…it's women's business and men's business…we're so lucky to be able to have a male and a female [Aboriginal Liaison Officer] because some males [patients] might not want to talk to a female [Aboriginal Liaison Officer]"* (Brittany).

Some Aboriginal and Torres Strait Islander patients were perceived to take longer to open up to clinicians about their symptoms due to prior negative experiences in health systems. Clinicians reported mitigating this by having group discussions and*"…identify[ing] who the key support is in that family. So sometimes it might be a daughter, it might be an auntie"* (Murray). Treating Indigenous Peoples was seen as a process where rapport with the clinical team was built over time. A measure of success was whether the patient opted to come into the clinic without a family member present: *"… we have a lot of Aboriginal*

patients who don't want to open up. A number of them, over time, develop rapport with the dialysis nurses and start discussing [their symptoms]" (Bardu).

When asking questions to assess symptom burden, clinicians used intuition to determine if patients were confused about medical terms (e.g., facial expressions) and adapted the explanation accordingly (e.g., using more straightforward language), or avoided specific topics (e.g., death): *"I remember when I use words in particular, like death, for some of the Indigenous patients, I think it was not taken very well, so I changed my tools since then"* (Lucas).

One clinician reported cultural beliefs about healing were a barrier to managing symptoms experienced by Aboriginal and Torres Strait Islander patients, so they educated these patients on the importance of dialysis to manage symptoms: *"one of my patients, she was quite even averse to going on dialysis… she thought that natural forces or natural therapy would maintain her renal function and she wouldn't need dialysis"* (Lucas).

Sub-theme: Symptom assessment and management strategies to overcome language and cultural barriers for patients who are culturally and linguistically diverse (CALD). Interpreters were infrequently used to translate conversations about symptoms due to the availability of family, carers and clinicians who spoke the patient's preferred language. Family and carers were crucial to facilitating communication between staff and patients from CALD backgrounds about a patients' symptoms. Families translated symptoms reported by patients during consultation to: help clinicians capture patient-reported symptoms, remind patients of concerning symptoms to raise, help staff educate patients about the importance of treatment adherence to manage symptoms and explain the context behind cultural approaches to health. Some clinics had nurses from multicultural backgrounds who were proficient in the languages their patient population spoke.

Clinicians reflected that building trust and rapport with CALD populations was important and helped them provide culturally appropriate care. They worried about not establishing rapport or breaking rapport once established: *"the main thing is not to risk rapport. You just want to make sure that you're doing the right thing"* (Gemma).

Clinicians also acknowledged the importance of educating patients on haemodialysis to manage their symptoms because of varied health literacy and perceptions about Western medicine*: "I think people that have English as their second language it's even more important that they understand us and the expectations of being a dialysis patient…we make that little more effort to make sure that they understand"* (Gabriella).

Sub-theme: Clinic approaches to assessing and managing symptoms in extremely frail patients. Participants shared that treatment options for symptoms were carefully considered, as patients were often elderly and had complex co-morbidities to manage: *"it's a very careful balance between treating their symptom and how well they are, and what medication is available to treat the symptom... medication can cause of lot of side effects"* (Gemma). For example, alternatives to pharmaceutical interventions, such as evening primrose oil, were recommended for itch due to the lack of side effects. Again, informal verbal symptom monitoring was used to monitor the response to treatment of certain symptoms (e.g. itch) with a follow-up call in between clinic visits.

3.5 Discussion

This study addresses a significant gap in our understanding of current practices for assessing, monitoring, and managing kidney failure symptoms in haemodialysis units in Australia. Overall, clinicians (with and without experience of using PROMs) highlighted the importance of building and maintaining rapport with patients to facilitate open, verbal conversations

about a patients' symptoms. Clinicians relied on patients to highlight burdensome symptoms without needing to use formal symptom questionnaires such as PROMs. Some clinicians were unsure of the value of assessing and monitoring non-dialysis specific symptoms if there were no referral pathways (e.g. allied health) or treatment options for patients considered frail or their health status had significantly deteriorated because of kidney failure.

Contrasting existing literature [20], clinicians who had yet to use PROMs, and many who had used PROMs, did not welcome the idea of ePROMs as part of treatment for kidney failure, mainly because of well-established clinic workflows where a nurse-led model of care meant patients had rapport and trust in their allocated nurse and had opportunities to discuss symptoms many times a week when they were scheduled for haemodialysis.

Challenges we report, which included difficulties in accurately assessing symptoms due to their subjective nature, time constraints in busy dialysis units, and the need for more training and resources, are not unique to our context but reflective of broader systemic issues in healthcare. However, our study reported unique findings around the perceived benefits of asking verbal open-ended questions. For example, clinicians captured contextual information such as a patient's socioeconomic status and goals that helped clinicians shift their patients away from a 'sick role' to seeing the ability to 'live well' whilst being on haemodialysis. Another important contribution of our study is how symptoms were captured across different populations, namely patients from CALD and First Nations backgrounds.

Overall, there was a preference to ask verbal, open-ended questions as an informal way to identify patient-reported symptoms. Clinicians reasoned this was an appropriate standard of care as it enabled rapport building between themselves and the patient and, if available, allowed for appropriate and timely referrals to renal supportive care and allied health services. Clinicians believed they had the expertise to assess symptoms. Existing

evidence, in a dialysis population consisting almost entirely of Caucasian patients, clinicians inaccurately recognised the presence or severity of symptoms, when compared to patient scores from IPOS Renal [21]. No matter how patient-reported symptoms were identified (either verbally or using PROMs), it mattered *how* this information would be used to improve a patients' health outcomes. The time patients spend sharing their experiences should be followed up with a review and appropriate action, which was a priority for clinicians in this study.

Clinicians shared doubts and apprehension about using formal symptom assessment tools such as PROMs. However, a qualitative study with participants in the SWIFT pilot study suggested that patients and clinicians perceived tablet-based electronic PROMs to enable efficient, systematic, and multidisciplinary approaches to symptom monitoring, to improve the *quality not quantity* of a patient's life [10], congruent with the goals of clinicians in this study. Some clinicians felt a sense of futility to symptom monitoring, given the often 'incurable' nature of patient-reported symptoms. However, evidence suggests just asking patients about symptoms has therapeutic value for the patient [10] as part of a person-centred approach to care. Person-centred approaches to care encourage actively listening to, respecting and responding to a patients' needs and preferences for treatment [22, 23]. Some high-income countries have adopted person-centred models of care and use PROMs as a tool to enable the conversation to shift to what matters to the patient and promote adherence to treatment protocols.

Many clinicians, especially nephrologists, mentioned that short consultations (often 10-20 minutes) were the ultimate barrier to assessing and monitoring symptoms, despite evidence that symptom burden was a priority for haemodialysis patients. However, in Australia, no legislation exists to limit clinic consultations. Using formal symptom

assessment tools, like PROMs, may help circumnavigate time constraints in clinics where clinicians do not have time for long discussions by flagging possibly concerning scores and health outcomes that matter most to patients at a glance. Therefore, if clinicians see the value and benefits of assessing and monitoring symptoms, it may encourage them to factor PROMs into the clinic workflow.

Strengths and Limitations

This study incorporates a diverse range of clinician perspectives, including those from various specialties and professional backgrounds. This breadth of insight is complimented by the different settings representing metropolitan, rural, public and private haemodialysis centers. This geographical diversity highlights the variability in symptom management practices and the unique challenges faced by clinicians in different communities. For example, the participating Victorian sites were situated within a community with a high Indigenous population and had specific clinic practices to engage Indigenous Peoples, in comparison to some metropolitan Queensland and New South Wale private clinics who did not report currently having patients from CALD backgrounds or Indigenous Peoples receiving dialysis in their centre.

Some limitations include few palliative care physicians who may have additional pathways for assessing and monitoring non-dialysis specific symptoms because their focus is conservative care where improving quality-of-life is prioritised. The clinicians who accepted the study invitation may have been especially engaged in trials and research and therefore clinicians unfamiliar with research may not have participated. Future research is also required to determine the transferability of findings to other Australian states and territories with known socioeconomic disparity in the community (e.g., Northern Territory).

Implications

Capturing patient-reported outcomes (PROs) is important when treating patients with kidney failure because symptoms significantly impact a patient's quality of life. The SWIFT involves using PROMs as an intervention to systematically capture PROs, aiming to improve patient health outcomes by standardising how symptoms are assessed, managed and monitored in a haemodialysis context. PROMs can facilitate earlier identification of symptoms that may be missed with verbal, ad hoc symptom monitoring, providing clinicians with an opportunity to intervene to alleviate symptoms and improve patients' quality of life whilst on haemodialysis.

Conclusion

When symptoms were assessed and managed, clinicians preferred to use open-ended verbal questions rather than PROMs because informal, verbal conversations were perceived to develop and maintain rapport with patients. Most nephrologists reported they did not have time to assess and manage symptoms or did not have access to PROM data to use in clinical consultations. Some clinicians who have collected symptom data felt there was nothing that could be done to manage the generalised symptoms experienced by patients with kidney failure, either due to the frailty of the patient, the lack of medical treatment options, or the lack of referral options to allied health. Some clinicians reported PROMs did not ask questions in a culturally appropriate way for patients from CALD backgrounds and Indigenous Peoples, thus a patients' family, clinician's judgement and Aboriginal Liaison Officers were important to help clinicians care for these populations.

Author contributions

Study conceptualisation and design: RLM, MA. Data collection: MA, SH, JN. Data analysis: JN, MA, RLM. Main draft of manuscript: JN, RLM. Manuscript revision and refinement: JN, RLM, MA, PB, AV, SJ, SM, CR, BK. Supervision: RLM, CR, BK.

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4. Discussion

Monitoring self-reported symptoms allows clinicians to understand their patient's experience with their chronic condition(s) and the impact on their health-related quality of life (HRQL). Patient-reported outcomes (PROs) assess HRQL, symptom burden, and responses to treatment to facilitate shared decision-making based on a patient's preferences. This can lead to more personalised care plans and timely interventions to alleviate symptom burden. PROs have been long used as clinical trial endpoints and routinely in cancer settings, but there are gaps in our understanding of their implementation in routine care of other chronic health conditions, namely kidney failure as well as in historically marginalised communities.

The aims of this thesis were to:

1. Synthesise existing evidence about facilitators of patient-reported outcome measure (PROM) completion by people from culturally and linguistically diverse (CALD) backgrounds and Indigenous Peoples.
2. Recommend ways to promote PROM completion by people from CALD backgrounds and Indigenous Peoples.
3. Understand how PROs are assessed and monitored for patients with kidney failure in Australian haemodialysis centres.
4. Understand how symptoms are monitored in Australian haemodialysis centres for people from a CALD background and Indigenous Peoples.

4.1 Chapter 2, Systematic Review: Aim 1 and 2

To ensure the benefits of PROMs can be experienced by all communities, and to avoid the unintended consequence of increasing health disparities, we need to consider the needs of

under-served groups and identify approaches to ensure greater inclusion of CALD communities and Indigenous Peoples in PROM completion initiatives.

In a systematic review of HRQL, PROMs used for Indigenous Peoples showed limited examples of Indigenous-specific PROMs [1]. Responding to the lack of PROMs co-developed with Indigenous Peoples, 13 guidelines were developed to outline how to facilitate this [2]. The focus of the guidelines was to engage Indigenous Peoples in the consultation and development process so PROMs are relevant and respectful of their cultural values and health perspectives. For Indigenous Peoples experiencing chronic illness, trust is a core component for engagement and authenticity in reporting their health outcomes and experiences [3]. Trust can be fostered as early as the pre-development stages where it is important to invest time and infrastructure to build relationships between researchers and Indigenous Peoples to create meaningful partnerships.

Not only is there a lack of PROMs designed specifically for CALD communities and Indigenous Peoples, Chapter 2 highlighted the fragmented global strategies to promote the completion of PROMs in these populations. Recommendations were made based on available evidence and within the context of PROM implementation in New South Wales, Australia. The strategies suggested by people from CALD backgrounds included: providing information about how to use electronic PROMs, facilitating self-completion, and offering different modes of completion (paper-based, digital). The strategies suggested by Indigenous Peoples in the review included: clarifying the role and purpose of PROMs, offering verbal completion, and community consultation during the design, development and implementation of PROMs to ensure cultural appropriateness and sensitivity. Clinicians reported increasing availability and system-wide support of culturally and linguistically appropriate PROM translations would promote their use.

4.2 Chapter 3, Qualitative study: Aim 3 and 4

Haemodialysis is a common treatment for kidney failure and significantly influences a patient's HRQL. Although it is known that pain, fatigue, restless legs, itching, anxiety and depression are common and significant burdens experienced by patients on haemodialysis [4], to date, there is a lack of published literature about how these symptoms are assessed, actioned and monitored in Australian haemodialysis centres. Symptoms experienced by patients with kidney failure are poorly understood and managed, despite guidelines about how to alleviate these symptoms using pharmacological and non-pharmacological treatments [5]. This thesis bridges the gap in understanding the workflow of how symptoms are identified and then managed in Australian haemodialysis centres.

Chapter 3 leveraged a randomised controlled trial, SWIFT, to shed light on current practices for assessing, reporting, and acting on kidney failure symptoms. Amongst nephrologists interviewed, there was a focus on biomedical markers of health status, such as sodium, phosphate and potassium levels in patients' blood. However, evidence has long highlighted that symptoms affecting HRQL and their secondary ramifications (such as losing independence, being a burden to family and friends, not being able to take care of their family, and not being able to work) are more important to patients than clinicians perceived [6]. It is important to note that although symptom assessment and monitoring in haemodialysis contexts may not entirely eliminate patients' symptoms, it can allow a patient's goals and priorities to be highlighted during clinical encounters, helping healthcare teams to work together with patients to make decisions on treatment for a patient's remaining years of life.

Chapter 3 reported on 'usual care' for assessing and monitoring in Australian haemodialysis centres in the absence of the trial intervention. All clinicians interviewed

described that they asked general, verbal questions to capture patient symptoms. This approach was described to help build and maintain rapport with patients and allow them to bring up what symptoms were a priority to them. PROMs, for some clinicians, were an important tool that complimented routine symptom assessment and helped systematically capture PROs that might otherwise have been forgotten or overlooked in busy clinics. PROMs were seen to complement blood tests because they provided information about the burden of a patient's symptoms on their day-to-day life, guiding clinical decision-making about the most appropriate treatment and/or referral pathway to allied health. Importantly, even though clinicians reported general practices when caring for CALD and Indigenous populations, rather than specific symptom assessment approaches, we can build a picture of how culturally appropriate symptom assessment methods can be integrated for patients with kidney failure. This can lead to more accurate symptom monitoring, better patient engagement, and ultimately, improved health outcomes for these populations and narrowing the gap in our understanding of their health outcomes.

4.3 Implications

Symptom assessment and monitoring can help facilitate person-centred models of care because a patient's health is examined more holistically. On an individual level, increased PROM completion by people from CALD backgrounds and Indigenous Peoples can enhance clinician-patient communication despite language and cultural barriers, increase patient engagement in clinical decision-making; and promote holistic care beyond managing medical test results [7]. Empowering people from CALD backgrounds and Indigenous Peoples to engage in clinical decision-making can encourage them to be active healthcare consumers and give them a voice in their care, especially if their community has historically faced marginalisation or experienced systemic barriers to accessing equitable healthcare. This

involvement can lead to more culturally sensitive and effective healthcare outcomes. Additionally, clinicians are provided data-driven insights about their patients' responses to treatment and can promote interdisciplinary collaboration (e.g., referral to allied health or community support) to manage patients' self-reported symptom burden, which has been historically a challenge in this population [4].

It is important to acknowledge the broader health service delivery implications of increasing PROM completion in routine care settings. These include using PROM data to guide quality improvement initiatives by comparing health outcomes across populations; identifying gaps in the provision of healthcare across populations; identifying areas where clinicians need further training (e.g., symptom monitoring for patients with kidney failure); and resource allocation within and between services or clinics [8, 9]. PROM data quality for aggregated use relies on data completeness; missing PROM data from CALD communities and Indigenous Peoples can compromise the interpretation and value of PROMs collected by health services [10]. This highlights an important consideration for health service improvement initiatives because missing data from these populations can reduce the statistical power to detect a health intervention effect, increasing the risk of false-negative findings (or type 2 errors) [11] or decisions about treatment effectiveness are made without the voices of CALD communities and Indigenous Peoples contributing. Low PROM completion by CALD communities and Indigenous Peoples has important health service delivery implications that cannot be ignored. Therefore, addressing this in Chapter 3 is an important step towards understanding how PROs can be assessed in these populations, to work towards greater representation of CALD communities and Indigenous Peoples' voices in health service delivery.

If PROMs become more standardised and institutionalised within healthcare systems, there is a risk that the focus may be on audit, performance measurement, and reimbursement. This could lead to an unintended scenario where the focus shifts from personalised, person-centred care. Clinical rapport and professional judgment, reported to be integral to patient care in Chapter 3, may become compromised as a result. It is crucial for future research to explore strategies that balance the use of PROMs with the need for clinical empathy, individualised care, and meaningful clinician-patient communication. This could involve developing frameworks that guide clinicians in using PROMs to complement verbal symptom assessment and build trust and rapport, not just for patients on haemodialysis but more broadly as part of person-centred approaches to care.

4.4 Strengths and limitations of this thesis

As the strengths and limitations of each study have been provided in more detail in the respective chapters, this section will focus on the overall strengths and limitations of the thesis.

4.4.1 Strengths

Notably, this thesis addressed an important gap in PROM implementation in marginalised communities including people from CALD backgrounds and Indigenous Peoples, broadly in clinical settings (Chapter 2) and specifically for patients with kidney failure being treated with haemodialysis (Chapter 3). Chapter 2 went beyond simply listing barriers to implementation, which are largely known, to instead synthesising the internationally published literature on strategies to promote PROM uptake in these populations for a more opportunity-based framing about the potential for all patients to provide feedback on their health to direct care. Chapter 3 helped fill a gap in the published literature about specific symptom monitoring practices in these populations in a haemodialysis setting.

Capturing symptom assessment and monitoring practices and preferences can give insights into how and where to incorporate PROMs within clinical care to assess outcomes that matter most to patients. To date, there has been minimal literature documenting how haemodialysis centres across Australia (including rural regions) assess and monitor PROs, and this is problematic given the significant symptom burden faced by patients with kidney failure that remains potentially unaddressed. By now documenting the importance of informal, verbal symptom monitoring, we can understand potential reasons why PROMs are not accepted or used by clinicians in this context. This is the foundational understanding required to work towards striking a balance between preferred symptom monitoring practices and using PROMs as a systematic way to capture and monitor symptoms.

4.4.2 Limitations

Focusing solely on kidney failure may limit the applicability of the findings to other chronic conditions. Different health conditions (e.g., cardiovascular diseases, cancer) may involve distinct symptom profiles, psychosocial factors, and treatment regimens that could influence symptom assessment and monitoring practices differently. For example, cardiovascular conditions may not require as much 'face-to-face' contact as required by patients on haemodialysis and the symptom trajectory can fluctuate (rather than consistently declining as typical for a patient with kidney failure), requiring more episodic care aligned with clinical events. In this context, cardiovascular clinicians may prefer the digital collection of PROMs, rather than informal verbal symptom monitoring, to help record information about patients they see infrequently.

Participants in Chapter 3 were only interviewed once, either pre- or post-SWIFT and not at both time points. Therefore, potential changes in attitudes about PROMs were not captured. In future, as new sites are onboarded, the SWIFT team may consider interviewing

the same participants six to 12 months post-trial to understand if participants maintain the same attitudes and perspectives about using PROMs.

4.5 Future Directions

4.5.1 Current research to address gaps

This thesis emphasised the low number of strategies specifically designed to increase PROM completion by people from CALD backgrounds and Indigenous Peoples - a call to action for health services. To address this, work is planned to examine what makes PROMs acceptable to CALD communities and their treating teams to elucidate specific areas that need to be considered during PROM implementation. During my candidature, I have been involved in a program of research that aims to address this gap. PROM-PATH is an NHMRC Partnership Project that leverages the New South Wales Patient-Reported Measures (PRMs) program. The NSW PRMs program incorporates PRMs into everyday clinical practice by enabling patients and multidisciplinary healthcare teams to capture, review and act on data in a timely and holistic way. The benefits of the planned PROM-PATH qualitative study [12] include: 1) capturing what makes PROMs acceptable across cultures to address the gaps identified in Chapter 2; 2) extending the findings from the trial setting in Chapter 3 to routine care settings and; 3) gaining perspectives from patients with kidney failure to complement the clinician perspective reported in Chapter 3. Preliminary data from the PROM-PATH qualitative study has suggested that to change the culture of symptom monitoring to routinely include PROMs and reduce perceived barriers, clinicians require: 1) flexibility in which tools to collect; 2) freedom to use their judgement about when to administer PROMs; and 3) training and support in managing or referring for symptoms that are beyond their speciality (e.g., dietitians identifying psychological distress).

The reality is that implementation is not, and cannot, be 'perfect'. PROMs use in real-world practice outside of controlled environments such as trials are largely influenced by resourcing (staff, time, cost, availability of interpreters), clinician characteristics (willingness to modify their practice, attitudes and values) and patient characteristics (propensity to adhere to health interventions, unique symptom trajectory, personal contexts etc) - the combination of which cannot always be anticipated, controlled or accounted for. However, there has been extensive work undertaken to identify optimal methods for PROMs use and implementation into practice, with guidance documentation developed by leading bodies in patient-reported outcomes such as PROTEUS and the International Society for Quality of Life Research (ISOQOL) [13-17].

Chapter 3 reported a sub-study within the SWIFT program of research. Generally, trials are associated with higher PROM completion and higher satisfaction of PROMs than occurs in real-world routine care. One of the clinical cohorts of interest in future research is Renal Supportive Care, which can provide insights into the disconnect between the high uptake of PROMs within trials and the poor uptake of PROMs in real-world practice. Beyond Renal Supportive Care, there are other cohorts of interest within PROM-PATH to capture the specific needs and disease trajectories of different chronic conditions to help recommend specific time points that can be used to administer PROMs beyond the rigid structure provided by a trial. This may also encourage nephrologists to see the value of using PROMs because PROs are captured at clinically relevant time points to facilitate timely action to alleviate symptom burden and improve their patients' therapeutic outcomes.

4.5.2 Future research

Another important consideration is to not discredit the importance of verbal, informal symptom assessment and monitoring, as preferred by clinicians in Chapter 3. If clinics decide

to incorporate PROMs to systematically capture PROs, future implementation initiatives should consider current clinic workflows and clinician preferences and 'on-the-ground' work practices to decide the most appropriate ways to incorporate PROMs into workflows where resource and time burdens can be minimised. Leveraging artificial intelligence in voice recognition software may be a useful way to capture PROs through verbal symptom monitoring, transforming verbally captured PROs in a format that allows for data visualisation and sharing amongst multidisciplinary care teams. This could make it easier for patients and clinicians to use PROMs without disrupting the preferred symptom assessment and monitoring methods.

One insight from my research, as part of PROM-PATH, is the bureaucratisation of PROMs, which is particularly relevant in the context of clinical practice. As PROMs become more standardised and institutionalised within healthcare systems, there is a risk that they may be used more as a tool for administrative purposes rather than to enhance patient care. This trend raises concerns about the unintended impacts of such formalised measurement systems on the therapeutic relationship between patients and clinicians. The growing use of PROMs for audit, performance measurement, and reimbursement purposes could lead to a scenario where the focus shifts from personalised care to fulfilling bureaucratic requirements. For example, clinicians feel pressured to focus on quantitative measures rather than engaging in nuanced discussions with patients about their health.

A valuable future direction for this research would be to explore the perspectives of patients and allied health professionals, particularly renal dietitians, on the completion and utility of PROMs to inform their clinical practice. While the thesis focussed on healthcare professionals directly involved in haemodialysis, it would be beneficial to examine how allied health professionals, such as dietitians, perceive the value and impact of PROMs,

offering different opinions of their usefulness and relevance. Based on this gap, the eligibility criteria in the planned PROM-PATH study includes this population of health professionals. Furthermore, the SWIFT study team has published patient perspectives on completing PROMs as part of the pilot study, but the patient voice as part of the SWIFT main trial is equally important. An additional sub-study has been considered to explore this perspective.

4.6 Conclusion

Bridging the gap between collecting PROs for clinical trials and the implementation in routine care requires: 1) specific strategies to promote the completion of PROMs by people from CALD backgrounds and Indigenous Peoples as this is currently lacking and needs advancement; and, 2) understanding what 'usual care' is for assessing, managing and actioning PROs in certain chronic conditions, such as kidney failure. Ultimately, symptom assessment and monitoring using PROMs may not eliminate symptoms of chronic conditions but allow a patient's goals and priorities to be heard during clinical encounters, facilitating shared decision-making about the best therapeutic options to help patients live as well as possible.

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5. Appendices

5.1 Chapter 2 Supplementary Files

Supplementary File 1: Electronic database search strategy

Topic terms: Limited English Proficiency

1. “Transients and Migrants"/
2. "Emigrants and Immigrants"/
3. Ethnicity/
4. Refugees/
5. Exp Cultural Diversity/
6. “Limited English Proficiency”/
7. exp Indigenous Peoples/
8. (migrant* or immigrant* or emigrant* or "culturally adj1 linguistically" OR ethnic* OR “cultural* adj1 divers*” OR refugee* OR “CALD” or multi-lingual* OR multilingual* OR “limited English proficienc*” OR “English as a second language” OR “non-English speaking background” OR First People* OR Native OR Torres Strait Islander* OR Aborigin* OR ATSI OR Oceanic Ancestry* OR First Nation* OR Indigenous* OR Aotearoa* OR Inuit* OR Maori* OR Hawaiian OR Pacific Islander* OR North American Indian* OR American Indian* OR Alaska Native* OR tribe*).ti,ab,kw.
9. Or/ 1-8

Intervention terms

10. Patient Reported Outcome Measures/
11. (“patient-reported outcome*” or “patient reported outcome*” or “patient reported-outcome*” or patient-report*).ti,ab,kw.
12. 10 or 11

Outcome terms

13. (implementation adj2 clinical*).mp.
14. (facilitator* or enabler* or uptake or utili?ation or fea?ibility or barrier* or strateg* or increase* or engagement or “implementation barrier”).mp.
15. (clinical or routine or regular* or “person-centred care” or “person-centered care” or “patient-centered care” or “patient-centred care”).ti,ab,kw.
16. (perspective* or view* or experience*).ti,ab.
17. Or/13-16

Study Design terms

18. (qualitative or (interview$)).ti,ab,kw.
19. semi-structured.ti,ab,kw.
20. focus groups.ti,ab,kw.
21. survey* and questionnaire*/
22. patient perspective.ti,ab,kw.
23. (mixed method* or mixed-method*).ti,ab,kw.

24. Or/18-24
25. 9 and 12 and 17 and 24

Exclusion criteria terms

26. p$ediatric.ti,ab.
27. (children or child or infant).ti,ab.
28. youth.ti,ab.
29. adolescent*.ti,ab.
30. in vivo.mp.
31. in vitro.mp.
32. historical article.pt.
33. letter.pt.
34. comment.pt.
35. editorial.pt.
36. (proxy or proxies).ti,ab.
37. protocol.ti.
38. (validation or validating).ti.
39. psychometric.ti.
40. Or/26-39
41. 25 NOT 40
42. Limit 41 to humans
43. Remove duplicates from 42
44. Limit search 2000- current

Supplementary File 2: PRISMA checklist

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title page
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2.1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	2.3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	2.3.4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	2.4.2
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	2.4.1
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	2.4.3
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	2.4.3/4
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	n/a
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	n/a
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	2.4.3/4
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	n/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	n/a
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	n/a
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	2.4.4
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	n/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	2.4.5

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	2.5.1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	2.5.1
Study characteristics	17	Cite each included study and present its characteristics.	2.5.2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	n/a
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	n/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	n/a
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	2.6
	23b	Discuss any limitations of the evidence included in the review.	2.6
	23c	Discuss any limitations of the review processes used.	2.6
	23d	Discuss implications of the results for practice, policy, and future research.	2.6
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Title page/abstract
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Title page
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Title page

5.2 Chapter 3 Supplementary Files

Supplementary File 1: Standards for Reporting Qualitative Research

Table 1
Standards for Reporting Qualitative Research (SRQR)[a]

No.	Topic	Item
	Title and abstract	
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
	Introduction	
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
	Methods	
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale[b]
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale[b]
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale [b]
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]
	Results/findings	
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
	Discussion	
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings

(*Table continues*)

SWIFT Sub-study Information for Clinicians

Adults receiving haemodialysis for kidney failure often experience many side effects like fatigue, pain, pruritus, sleep disturbance and reduced quality of life[1]. The Symptom monitoring WIth Feedback Trial (or SWIFT) will be enrolling patients in the unit and asking them to fill out questionnaires related to their quality of life to determine if symptom monitoring (using the IPOS Renal Questionnaire) improves health-related quality of life (measured by the EQ-5D-5L questionnaire) and cause-specific mortality.

SWIFT has commenced and will be conducted in your unit over the next year. As part of the trial, the SWIFT team would like to build a picture of what standard care for symptom monitoring looks like in haemodialysis units nationally. To determine this, we would like to ask you a few questions related to standard care for symptom management in your unit. This will be done in the form of a semi-structured interview. The interview should take between 20 to 30 minutes in total and will be audio-recorded so your responses can be transcribed at a later date.

Questions will relate to symptom management, quality of life questionnaire collection, what is done with the information if collected, referrals to Renal Supportive Care and how referred patients are managed.

Participation is voluntary – you do not have to be interviewed. If you decline to participate, your role in SWIFT will not be affected in any way.

If you have any concerns or questions relating to this part of the trial, please contact Chief Investigator Prof Rachael Morton (rachael.morton@ctc.usyd.edu.au) or Trial Coordinator Lavern Greenham (ph. 08 8128 4264 or email swift@anzdata.org.au).

Ethics approval for this sub-study has been obtained from the Central Adelaide Local Health Network (CALHN).

For any ethical issues relating to this trial, please contact CALHN HREC Executive Officer (Email: Health.CALHNResearchEthics@sa.gov.au ph. +61 7117 2229)

Reference: [1]Murtagh FE et al. Adv Chronic Kidney Dis. 2007.14(1):82-99.

Supplementary File 3: Interview topic guide

SWIFT Sub-Study: Current practice for symptom management in haemodialysis satellite centres
Topic Guide

The purpose of this semi-structured interview is to explore current practices for the management of symptoms in satellite haemodialysis centres.
Topic Guide Questions:

1. Name of haemodialysis satellite centre: __
2. Position of respondent: __
3. How long have you been a Nephrologist / renal nurse / Renal CNC?: _
4. *The next question is about your unit's practice:* Does your haemodialysis satellite centre use any symptom assessment measures for haemodialysis patients (e.g. IPOS Renal, POS Renal, KDQOL-36) as part of routine clinical practice? If so, which ones, and how do you go about administering these?
5. *(As an individual nephrologist, for patients under your care).* When do you ask about symptoms (either through a questionnaire or direct consultation), and how often?
6. Who do you decide to measure (all patients or patients with particular criteria)?
7. How do you go about *symptom assessment* with . . .
   (i) culturally and linguistically diverse (CALD) patients?
   (ii) Those who are frail?
   (iii) those who appear to be doing well
8. If a patient was found to have a high symptom burden (e.g. pain or itching) through your assessment, what would be done with this information, or any further steps that would be taken (e.g. discussion with multidisciplinary team, referral to specialist or other clinical personnel or programs)?
9. *[If needed]* If a patient was not found to have a symptom burden through your assessment, what would be *done with this information,* or any further steps that would be taken (e.g. symptom assessment data stored in a local repository)?
10. In your centre, do patients generally get to keep a copy of their symptom survey results? If so, how would they receive this?
11. Are you ever surprised by a patient's results (e.g. IPOS Renal scores)? Do survey results ever tell you something you already knew/didn't know about a patient?

    Suggested probe: Can you think of a time you discovered something unexpected from a symptom assessment (either through a questionnaire or direct consultation)? What did you do with this information?
12. Aside from formal symptom assessment measures (e.g. IPOS Renal), do you use other methods for understanding symptom burden in your centre, and how does this occur? *[Other symptom scales like ESAS, other QOL questionnaires, medical history open ended questions]*

    if 'yes', make sure following sub-questions are explored

    (i) Can you provide us with an example of the kinds of assessment questions you would ask?

    (ii) What is done with this kind of information?

13. Is there anything you feel would make symptom assessment and management easier and more effective for haemodialysis patients in your satellite centre?
14. Is there anything else you'd like to tell us about symptom assessment and management for haemodialysis patients in your satellite centre?

Thank you!