

# Evaluation of an innovative *Live Strong* COVID-mitigating healthcare delivery for adults after starting dialysis in the Northern Territory: A qualitative study



Sara Zabeen<sup>a</sup>, Anne-Marie Eades (Aboriginal and/or Torres Strait Islander)<sup>b,c</sup>,  
Onika Paolucci (Aboriginal and/or Torres Strait Islander)<sup>d</sup>, Richard Modderman<sup>a,d</sup>, Clee Tonkin<sup>d</sup>, Kerry Dole<sup>d</sup>,  
Gwendoline Lowah (Aboriginal and/or Torres Strait Islander)<sup>d</sup>, Kirsty Annesley<sup>d</sup>, Jacqueline Kent<sup>d</sup>,  
Emidio Coccetti<sup>d</sup>, Anne Weldon<sup>d</sup>, Matthias Jing<sup>d</sup>, Deborah Roe<sup>d</sup>, Rebecca Jarman<sup>d</sup>,  
Anne-Marie Puruntatameri (Aboriginal and/or Torres Strait Islander and Indigenous Patient Reference Group member)<sup>d</sup>,  
Edna May Wittkopp (Aboriginal and/or Torres Strait Islander and Indigenous Patient Reference Group member)<sup>d</sup>,  
Wayne Alum (Aboriginal and/or Torres Strait Islander and Indigenous Patient Reference Group member)<sup>d</sup>,  
Tolbert Dharromanba Gaykamangu (Aboriginal and/or Torres Strait Islander and Indigenous Patient Reference Group member)<sup>d</sup>,  
Jaquelyne T. Hughes (Aboriginal and/or Torres Strait Islander)<sup>a,d,e,\*</sup>

<sup>a</sup>Rural and Remote Health, Flinders University, Northern Territory, Australia

<sup>b</sup>Faculty of Health Sciences, Curtin School of Allied Health, Kent Street Bentley 6102, WA, Australia

<sup>c</sup>Faculty of Health, University of Technology Sydney, 15 Broadway Ultimo 2007, NSW, Australia

<sup>d</sup>Royal Darwin Hospital, Northern Territory Department of Health, 105 Rocklands Dr, Tiwi 0810, Northern Territory, Australia

<sup>e</sup>Menzies School of Health Research, Charles Darwin University, John Mathews Building Royal Darwin Hospital Campus, 58 Rocklands Dr, Tiwi 0810, Northern Territory, Australia

## Abstract

**Purpose** During March 2021 to February 2022, within a local pandemic preparation and response phase in the Northern Territory (Australia), the New Start Dialysis Transition Programme (NSDTP) extended usual services by designing and implementing three activities aimed to support patients with kidney failure to *Live Strong* after starting dialysis: a) incorporation of COVID-safe education at group health education sessions, b) *Frailty to Fit* restorative physiotherapy and c) a COVID and culturally-safe, frailty-enabled transport service. This qualitative study evaluated these initiatives within the broader socio-environmental context.

\*Corresponding author.

E-mail address: [Jaqui.Hughes@flinders.edu.au](mailto:Jaqui.Hughes@flinders.edu.au) (J.T. Hughes).

© 2023 The Author(s). Published by Elsevier B.V. on behalf of Lowitja Institute (National Institute for Aboriginal and Torres Strait Islander Health Research Ltd). This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

<https://doi.org/10.1016/j.fnhli.2023.100001>





**Methods** The study was guided by an evolved Grounded Theory approach. Feedback was gained from 61 participants, involving Aboriginal and Torres Strait Islander people with lived experience of dialysis care, their family caregivers, health professionals and Indigenous Patient Reference Group members.

**Main findings** Multiple data sources and a related comprehensive thematic analysis generated six key themes: 1) COVID-safe education delivery enabled family learning, was culturally respectful and strengths-based; 2) physiotherapy was personalised and patients experienced enjoyment; and 3) the transport service accommodated frailty needs and supported COVID safety needs. Participants also reported that within the broader socio-environmental context *Live Strong* meant: 4) living with purpose and dignity; and 5) living for the family, culture and the Country. Thus, participants recommended that 6) health systems could enable patients to ‘Live Strong’ by providing cultural understanding and patient safety across all healthcare settings they used.

**Principal conclusions** Participants confirmed acceptability and recommended sustainability of three innovative services. These were designed, delivered and incorporated within usual care during the local COVID pandemic preparation and response. Success was credited to service flexibility that prioritised patient needs, family-inclusive care, and empathetic and respectful staff who had good cultural understanding of kidney care and strong team collaboration. Participants also recommended health systems to support the transferability of those success attributes to other healthcare settings.

**Keywords:** Aboriginal; Dialysis; End-stage kidney disease; COVID; Culturally safe; Live Strong

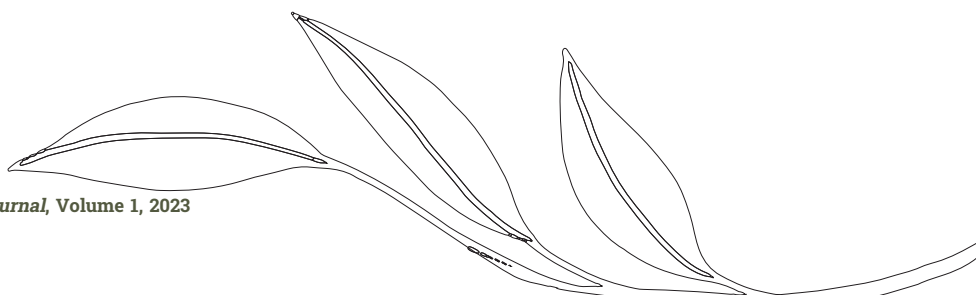
## Highlights

- The *Live Strong* project was invited, designed and implemented within the context of an anticipated high pandemic risk for patients within the Darwin, Northern Territory region. Aboriginal and Torres Strait Islander people were leaders of this work, as patient-users (and research participants), in clinical service provider roles and the Indigenous Patient Reference Group.
- The findings suggested that the study participants could identify ways that usually delivered Aboriginal and Torres Strait Islander-led healthcare evaluated within the *Live Strong* project helped patients to ‘Live Strong’.
- Participants’ feedback invited the successful elements of this *Live Strong* project—transport, physiotherapy and education—to be extended to other dialysis units they accessed.

## Introduction

Aboriginal and Torres Strait Islander people live with a high burden of end-stage kidney disease (ESKD), which is kidney failure that is not survivable without dialysis or transplantation, and they advocate for dialysis care closer to their homes, which affords connections to their Country, cultural practices and community who

can support holistic health needs (Cangini et al., 2019; Hughes et al., 2018). In the Top End of the Northern Territory, specialist dialysis service hubs situated in the Darwin region have required remote-living patients to leave their Country, homes and families (Hughes et al., 2019a). Social isolation, accommodation and transport challenges, unfamiliarity of the location and the health





system, language barrier and lack of access to culturally safe amenities have been identified as compounding challenges for patients and their family caregivers (hereafter referred to as caregivers) (Cangini et al., 2019; Hughes et al., 2019a; Scholes-Robertson et al., 2022).

In late 2019, Top End Renal Services (TERS) commenced the New Start Dialysis Transition Programme (NSDTP) to assist patients experiencing vulnerability during the period of transitioning to long-term dialysis treatment. To support health optimisation, clients had access to health management support from an experienced Aboriginal and Torres Strait Islander Health Practitioner, three nephrology specialist reviews and referral to multidisciplinary healthcare at other locations. This was offered within approximately 16 weeks, as this was a reasonably expected period that patients aimed to gain knowledge, confidence and mastery in their clinical management. The NSDTP worked collaboratively with the affiliated hospital dialysis unit who delivered thrice-weekly, nurse-assisted haemodialysis treatments, and the NSDTP supported patients to develop pathways to self-care dialysis, regional-based and remote-based assisted dialysis, and assessment for suitability for kidney transplantation. Thereafter, patients were referred to a home dialysis training program or continued with nurse-assisted haemodialysis. The NSDTP was led by experienced Aboriginal and Torres Strait Islander health professionals and its design was informed by locally conducted consumer-partnered health services research (Hughes et al., 2018; Hughes et al., 2019a; Hughes et al., 2019b; Hughes et al., 2019c). From 1 January 2021 to 31 December 2021, 46 of 84 (55%) adults who commenced long-term haemodialysis treatment at Royal Darwin Hospital Dialysis Unit participated in the NSDTP.

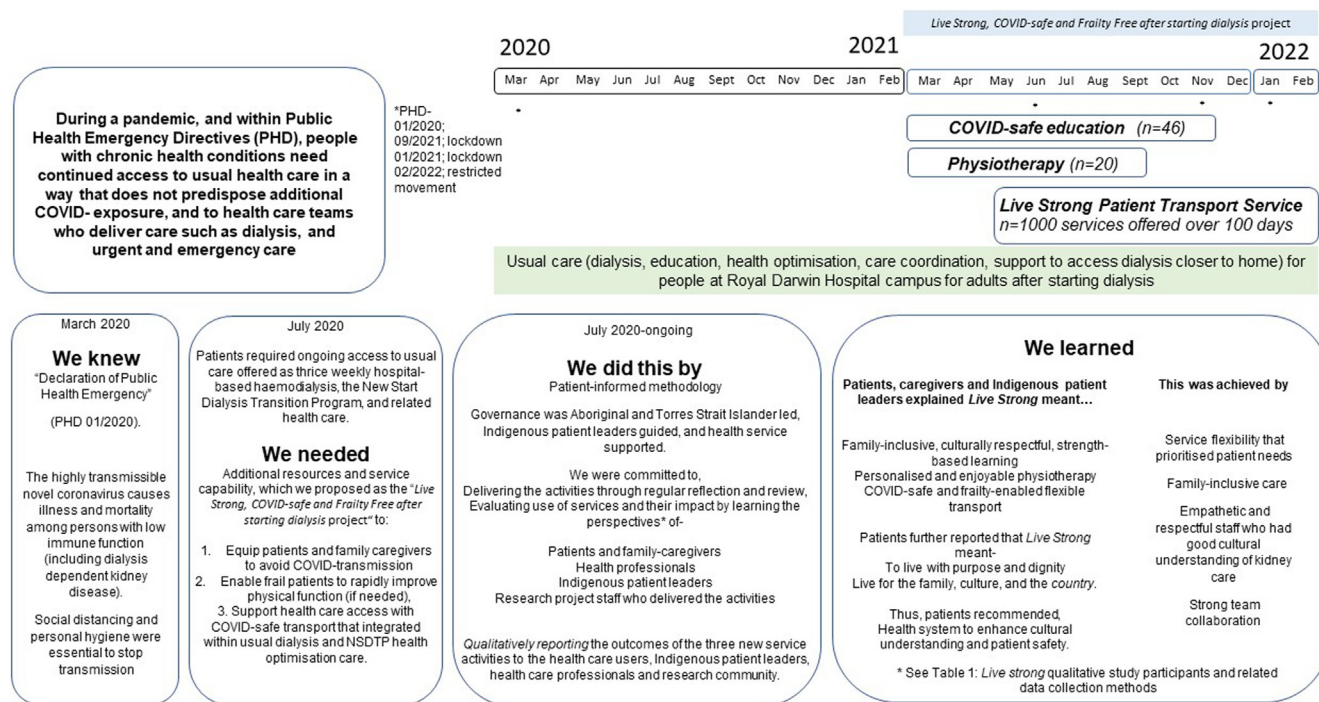
### 'Live Strong, COVID-safe and frailty free after starting dialysis' project

The COVID pandemic interrupted usual healthcare for everyone in 2020. People with chronic health conditions that lowered immune function, such as chronic kidney disease and kidney failure, were vulnerable to COVID-19 illness and mortality if they acquired the novel coronavirus (El Karoui and De Vriese, 2022). Three new service activities were designed and implemented to maintain a COVID-safe healthcare and learning environment for patients within the NSDTP (Figure 1).

The project had 46 NSDTP patients who consented to concurrent research participation in the *Live Strong* services and delivered by six project staff from March 2021 to February 2022. In brief, those services were:

- a) COVID-safe education: COVID-safe and self-management information relevant to people with ESKD was integrated within quarterly group education sessions and individual learning. Education, delivered by an Aboriginal and Torres Strait Islander Health Practitioner, included video resources, booklets, COVID-safe practice demonstration and confirmation of learning.
- b) Frailty to Fit: This physiotherapy program was delivered by a senior physiotherapist over 16 weeks. Frailty detection, documentation and physical restorative care were offered as individual and/or group exercise according to patient preference.
- a) Live Strong Dialysis Patient Transport Service: Transportation was specifically requested by patients, so that those with either lower immune function, frailty or service navigation challenges could access NSDTP-related appointments around demanding dialysis schedules. Additionally, staff at the hospital dialysis unit requested an integrated transport service to support clients' health maintenance through regular dialysis attendance





**Figure 1: Inputs, outcomes and learnings of the impact of three service innovations integrated within usual care during Northern Territory pandemic response**

and avoid compounding individual morbidity and critical illness from missed dialysis treatments (and hospital dialysis unit flow-on effects among the broader client cohort of that unit by emergency dialysis re-scheduling).

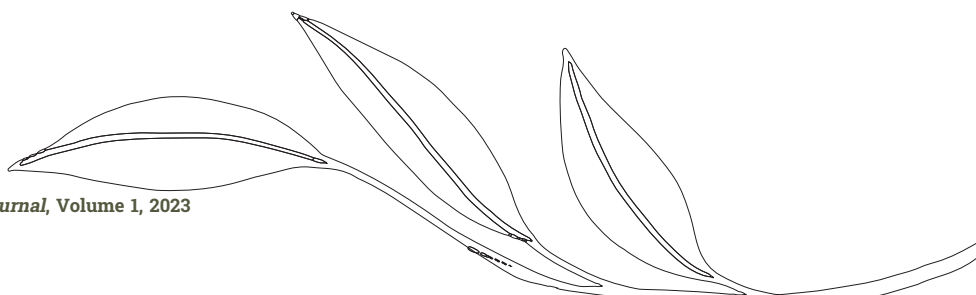
This study aimed to determine the acceptability and suitability of the three innovative services mentioned above. The key research questions were:

1. What does *Live Strong* mean to adults diagnosed with kidney failure?
2. How can *Live Strong* patients be supported by improving the services?

An Australian Indigenous health perspective was sought since many patients were Aboriginal and Torres Strait Islander people.

## Methods

Across an implementation and evaluation period of March 2021 to February 2022, 46 patients who accessed the NSDTP were eligible to participate in the *Live Strong* project services (COVID-safe education, physiotherapy and *Live Strong* transport). Twenty-seven of those 46 patients (59%) consented to participate in this study, which employed a qualitative methodology (Mills and Birks, 2014). Purposive sampling (Gentles et al., 2015) was used to recruit 61 participants comprising 27 patients, 10 caregivers, 4 Indigenous Patient Reference Group (IPRG) members and 20 health professionals. Feedback was gained through in-depth interviews, the standardised local hospital feedback forms, field notes and group reflective discussions (Table).





Purpose of data collection	Data source	Data collection method	Data collection period and duration	Participants (N)
Process evaluation of the quarterly scheduled group education sessions (maximal patient participation is one session)	Notes taken at group education sessions (three scheduled during this evaluation period)	Face-to-face	March–October 2021 (2–3 hours)	<b>45</b> 27 patients (59.25%) 10 caregivers (90% female) 8 health professionals (who delivered health information) (50% female)
Evaluation of the overall <i>Live Strong</i> project	Hospital feedback forms	Face-to-face	September–November 2021 (15–20 minutes)	<b>19</b> 11 patients (66.67% female) 2 caregivers (50% female) 2 IPRG members (50% female) 4 health professionals (50% female)
Evaluation of the overall <i>Live Strong</i> project	In-depth individual interviews	Telephone	January–February 2022 (20–50 minutes)	<b>13</b> 9 patients (22.22% female) 2 caregivers (100% female) 2 IPRG members (50% female)
Process evaluation of the <i>Live Strong</i> project	Notes taken at 4 <i>Live Strong</i> team reflective discussions	Either virtual or face-to-face sessions*	March–December 2021 (30–60 minutes)	<b>17</b> 11 study investigators (80% female) 6 project staff (50% female)
Process evaluation of the <i>Live Strong</i> project and Indigenous governance	Notes taken at 3 IPRG group reflective discussions	Face-to-face*	March–October 2021 (1.5–2 hours)	<b>10</b> 4 IPRG members (50% female) 6 project staff (50% female)
Process evaluation of the <i>Live Strong</i> project and Indigenous governance	Notes taken at 1-year end group reflective discussion	Face-to-face*	December 2021 (2 hours)	<b>11</b> 4 IPRG members (50% female) 2 study investigators (100% female) 5 project staff (40% female)

All 27 patients and 10 caregivers were exposed to one group education session, whose feedback was recorded in field notes. Of those 27 patients and 10 caregivers, 11 patients and two caregivers provided perspectives of the service innovations through hospital feedback forms, and a further nine patients and two caregivers attended in-depth telephone interviews. IPRG = Indigenous Patient Reference Group. \*Participants eligible for more than one feedback.

**Table 1: *Live Strong* qualitative study participants and related data collection methods**

The IPRG recommended in-person group ‘storytelling’ as the preferred way to collect data, as it allows expression of Australian Indigenous knowledge that fosters connectedness and reciprocity (Datta, 2018; Pope and Mays, 2020). However, individual telephone interviews were employed due to the local COVID outbreak during the formal evaluation period of the project (February 2022). In-depth qualitative interviews were conducted with the participants, using a Grounded Theory approach to allow for culturally responsive and sensitive approaches to explore participant experiences (Corbin and Strauss, 1990). To begin with, S.Z. asked an unstructured, open-ended question to initiate the interview: ‘please share your experience of the [service name. e.g. physiotherapy]’. An interview guide prompted further feedback to gain deeper understanding of the complexity associated with cultural understandings

and safety strategies for patients (Supplementary File S1).

To contextualise participant feedback, field note observations were concurrently recorded. All field notes were collected at the main study location (Royal Darwin Hospital) when healthcare was delivered. Notes were also taken at the *Live Strong* project’s operational and Indigenous governance meetings to inform how the services were delivered alongside usual care. These meetings were hosted in-person, when public-health directives permitted gatherings, at a health research facility within the Royal Darwin Hospital campus.

### Data analysis

Data were deidentified, audio transcribed and coded by a researcher (S.Z.) and reviewed by the research





team, where key themes and concepts were identified as emerging from the data. An iterative process of coding continued to identify patterns and connections between different codes to refine understanding of the six key themes. An evolved Grounded Theory approach (Chun Tie et al., 2019) was used to generate key themes through Thematic Analysis (Braun and Clarke, 2006). Evolved Grounded Theory captures participants' sociological perspectives on a phenomenon that stems from personal experiences and social interaction (Chun Tie et al., 2019). The key findings were shared with the IPRG members as part of the project's Indigenous Governance, and to seek feedback in the context and relevance of their cultural knowledge and patient expertise.

## Ethics and Governance

The IPRG provided project leadership around Indigenous Governance, Indigenous Data Governance and advocacy for patients. Site-specific ethics approval was granted by the Northern Territory Government (RGO EFILE2021/12495), Menzies School of Health Research Human Research Ethics Committee (2021-4023) and Flinders Northern Territory Human Research Ethics Committee (5582). The study was also approved by an Aboriginal Ethics Subcommittee that held power of veto over research involving Aboriginal and Torres Strait Islander people.

## Results

The findings of this study generated six key themes to reflect what helped patients to *Live Strong* after starting dialysis within the three new service activities: 1) COVID-safe education delivery enabled family learning, was culturally respectful and strengths-based; 2) physiotherapy was personalised and patients experienced enjoyment; and 3) the transport service accommodated frailty needs and supported COVID safety needs. Patients also reported that within the broader socio-environmental context, *Live Strong*

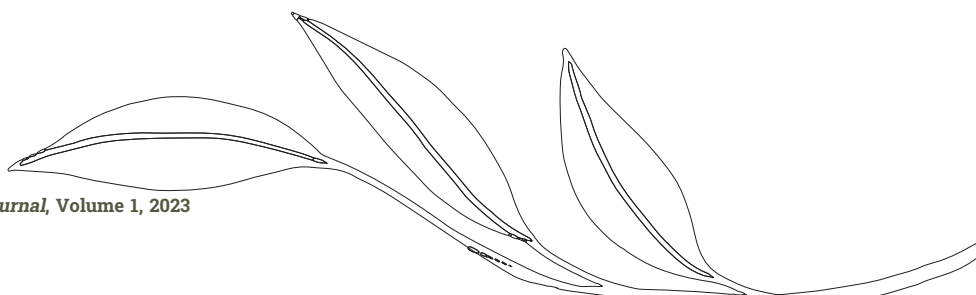
meant: 4) living with purpose and dignity; and 5) living for the family, culture and the Country. Thus, patients recommended that 6) health systems could enable patients to 'Live Strong' by providing cultural understanding and patient safety across all healthcare settings they used.

## COVID-safe education delivery enabled family learning, was culturally respectful and strengths-based

Patient qualitative feedback suggested that self-management education on transplant, dialysis and controlling fluid overload was most helpful at both individual learning and group education sessions. COVID-safe education and practices were also recalled by some patients who suggested that more educational programs were needed in the community, involving community leaders and health experts who could speak Australian Indigenous languages. In one of the three group education sessions delivered in 2021, a Services Australia Disability Support Pension Assessor was invited by the IPRG members, who explained how to apply for a Disability Support Pension; this session was highly valued by patients.

Study participants expressed that visual education materials were their preferred ways of learning (e.g. brief videos on kidney transplant). Some patients said that they would like to have self-study materials written in Australian Indigenous languages. Use of pictures, large fonts, less words and plain language were appreciated. Multiple patients explained that by using 'easy' (uncomplicated) English words, health professionals demonstrated respect, since English was not a first language of many participants. Patients also requested for repeat sessions to reinforce information and extend their learning.

Group education sessions also included informal caregivers. Field notes showed that both patients and





caregivers enjoyed these sessions and actively participated in all activities; this process acknowledged the importance of family involvement in care and promoted shared learning. Patients and caregivers could celebrate COVID-safe learning milestones, as patients were presented with a certificate of demonstrated competency in COVID-safe hand hygiene, mask use and social distancing. Another important aspect of the group education sessions was having a role model (expert patient within the role of peer support) who explained their experiences of training for home dialysis and being able to self-care.

Overall, patients appreciated the individual and group education sessions and according to the hospital feedback form that asked 'do you have any suggestions for improving what we do?' provided suggestions around more health information needs:

*I want to know more about dialysis. What does the iron injection do? I want to know how they work. (Patients who are not vocal) - they want more feedback on how kidney functions - they want to see their results. They want information. (P6, hospital feedback form)*

### **Physiotherapy was personalised, and patients experienced enjoyment**

Patient feedback suggested that the physiotherapy program was enjoyable. Patients also reported that personal strengthening guided by the physiotherapist helped them to plan and achieve living with dialysis closer to their home [remote location].

*Making me stronger – the physio. Haven't been to the hospital for a while. [Want to] go home, do dialysis on [remote island] – see family. (P11, hospital feedback form)*

One patient (P17) explained that group activities were particularly fun and promoted community

engagement, as they interacted with patients from different tribes. Most patients developed rapport with the physiotherapist, which was a motivating enabler to achieve their personal fitness goals. Participant comments revealed that the physiotherapist was empathetic and demonstrated respect (including respect for their culture).

*When I was sick, I lost my leg. I saw brother [physiotherapist], and he helped me. And I am walking now. (IPRG1, hospital feedback form)*

Within the group reflective discussions involving research staff, clinicians and IPRG, the physiotherapist identified the importance of patient-staff collaboration to support those good outcomes. Furthermore, clinicians confirmed receiving positive feedback from patients on the physiotherapy program, and those outcomes complimented the role and previously high functional support needs that were referred to the kidney occupational therapy (who prior to the *Live Strong* project was the only renal allied health provider supporting physical function needs for TERS). The IPRG members regarded the physiotherapy program as *the best* component of the *Live Strong* project, as it was showing results that helped patients stay out of hospital (avoidance of acute admissions) and patients were showing improved mobility. There were a few suggestions to improve the program: one patient requested to use an air-conditioned room (given the humidity) and floor mats to support their frail legs. Female participants also requested privacy to exercise, explaining that it was culturally inappropriate to exercise in front of other men.

### **The transport service accommodated frailty needs and supported COVID-safety needs**

The *Live Strong Dialysis Patient Transport Service (Live Strong bus)* had some unique features that were appreciated by all participants. They regarded the





service as reliable, flexible and culturally respectful. Participants reported the bus was mostly beneficial in supporting patients and caregivers to attend the group education and physiotherapy sessions. Drivers telephoned patients to confirm pick-up location and estimated arrival, which assisted patients to plan the sometimes prolonged time to walk to the agreed meeting area with their rollator frame and personal equipment. The *Live Strong* bus was identified by patients and caregivers as COVID-safe (e.g. hand sanitiser, provision of masks, spacing a few passengers across the whole 10-seater vehicle, regular wipe-down of high touch points, log of carriage so that potential contacts could be traced). The bus was also frailty-enabled, with customised handrails and secure stowage for low rollators and patients' equipment. Patients reported feeling physically secure with drivers whose driving speed and care took account for their physical vulnerability around fatigue, frailty and balance. During the COVID-19 lockdowns, health staff acknowledged the transport service's effectiveness, especially as there was much greater demand on the existing hospital transport system. The service supported patients who could not access other transport, and therefore vulnerable to missing dialysis, with consequent urgent out-of-hours emergency and related dialysis care.

Overall, the *Live Strong* project was appreciated and valued by patients and their caregivers.

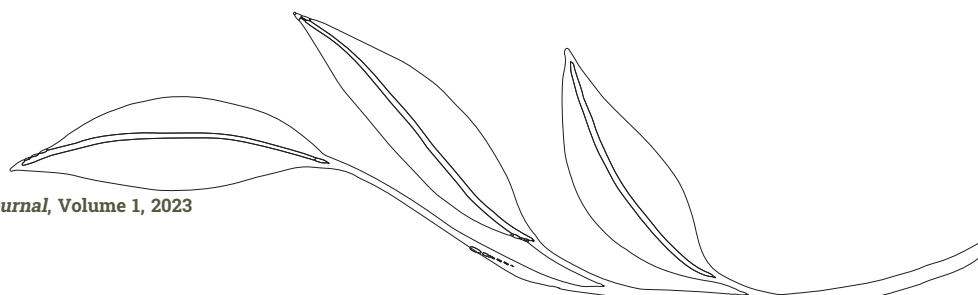
*I like how (physiotherapist) trains me and (Aboriginal and Torres Strait Islander Health Practitioner) teaches me about food. I feel happy about coming every time [Tuesday]. Bus is good. He came and picked me... I forget- so [I] need more info from (Aboriginal and Torres Strait Islander Health Practitioner): how much to eat, drink, keep me happy, not to worry too much. (P10, hospital feedback form)*

## **Live Strong means living with purpose and dignity**

Patients revealed how their illness impeded them from living a meaningful life after starting dialysis. Most reported that they could not work due to the severity of their illnesses. There was a sense of identity loss among patients when unable to work, support their family, or worse, unable to do basic household chores due to their frailties. Some patients expressed distress as they saw themselves as a burden on their family when unable to self-care. They explained that practicing self-care was a way to show resilience and maintain self-worth beyond their illness and related disabilities; this demonstrated self-advocacy of purpose. Having a partner or family was a major motivation towards self-management:

*I'm looking out for myself, I'm pretty tidy, I get up, I do my things, you know. I get up, I do what every other normal, you know, general housekeeping... You know, and I can't work anymore so I just make sure I have a clean house. I wash my own clothes; I fold my clothes. I got a girlfriend back there, you know, I've been keeping my own house for, you know. So yeah. (P17, interview)*

Creating or re-creating personal or social identity and their maintenance also improved overall patient satisfaction and wellbeing. For example, IPRG members, who were at different stages in their lived kidney care journeys, showed pride in having found this new 'job' (employed in research as leaders of innovative healthcare) of being able to advise and work with the health service through authentic representation of their people and culture. IPRG2 explained that being able to be identified as an IPRG member, having the related project branded uniform, and supporting healthcare access with the *Live Strong Dialysis Patient Transport Service* with its empowering and culturally significant logo were all significant aspects of their role in promoting Indigenous Governance and authority within the health system.







The IPRG members had the wisdom of lived experience as patients of the health service and could share their experiences to further improve the NSDTP program and help other patients to *Live Strong*. They repeatedly requested more psychosocial support to initiate a sense of purpose and meaning in life (e.g. kidney appropriate cooking classes, art therapies, outdoor education and physiotherapy sessions). These findings also reflected the views of the patients on their overall wellbeing.

### **Live Strong means living for the family, culture and the Country**

All patients explained that being with their family and community were crucial to them. Being relocated for dialysis access, they often had to stay apart from their families to receive necessary kidney care; COVID-related travel restrictions magnified this separation. This took a major toll on most patients, as they missed their family, homelands and bush food. Thus, having family support in Darwin was reported as beneficial.

*They (family) help me, they hunt for me, they get some bush medicine, and they encourage me. I get a lot of encouragement from my kids and grandchildren, my loved ones, you know. And it's better for me to see my grandchildren grow up next to me. And they cook for me, like deer or kangaroo, all the bush feed and that, even they bath me with some bush medicine. My daughters-in-law or my daughter, they all take turns to look after me. (P21, interview)*

All patients wished they could get necessary treatment closer to their homelands, and strongly demanded capacity building within their own community and health clinics. In the meantime, participants suggested to ensure that regional Aboriginal patients were receiving holistic kidney care within the current metropolitan settings. Patients and caregivers requested to improve the health system

culture and pay further attention to important social determinants such as culturally appropriate food in the hostels, more psychosocial supports within the health system and fulfilling their cost-effective housing needs.

### **Health system to enhance cultural understanding and patient safety**

All patients admitted that staff at the facility hosting the NSDTP were respectful, friendly and accommodating to their culturally appropriate health needs. However, a few patients provided differing feedback on care experiences at other clinical services they used. They revealed that sometimes they were not listened to, understood or believed when they expressed their health needs to staff. Some patients reported a personal experience of verbal abuse and mockeries from health staff.

Regarding holistic health experience and treatment safety, some patients reported poor memory, and one patient attributed this to a treatment side-effect. Based on their lived experiences, the IPRG members reflected that all dialysis units could improve the comfort of the dialysis chairs (that people sit in for four or five hours each session) since patients experience frailty and other symptoms of ESKD. They also requested more security at the overall health facility precinct, given that it was accessible by strangers; frail patients were particularly vulnerable to unwanted advances. Furthermore, patients wanted good COVID safety measures within all the dialysis units where they accessed care.

*Well at the moment with renal it's a bit hard. You know, we're sharing a building with close contact and positive cases, and then there's the people that have tested negative and we're sharing the one dialysis unit. I mean there should be a COVID-free dialysis unit just for patients that don't have COVID or haven't tested*





*positive or is not a close contact... we need a safe place for, just a place for isolation just for renal patients. [The COVID quarantine facility] is a bit too far for them [to be quarantined and then to go to the dialysis unit for treatments three times a week]. (IPRG4, interview)*

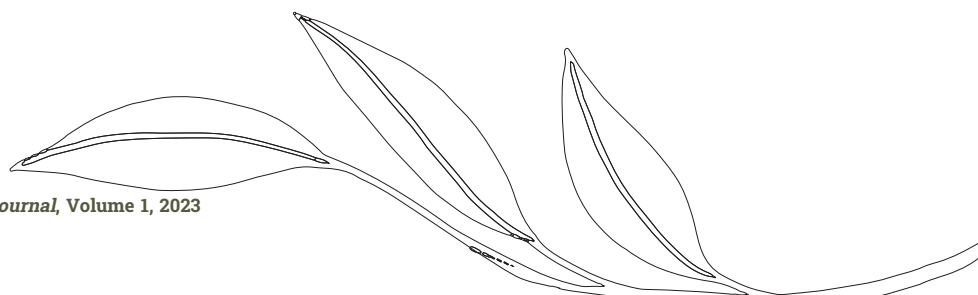
## Discussion

This study undertook a qualitative evaluation of three service activities implemented in the Northern Territory of Australia during the local COVID pandemic preparation and response. Participant feedback confirmed that family-inclusive education, personalised physiotherapy, and COVID-safe and frailty-enabled transport offered a culturally appropriate person-centred healthcare program, which demonstrated acceptability of the service innovations and met many patient-identified health needs. As per the Aboriginal chronic care and wellbeing models, identifying patient needs within their cultural context and meeting them accordingly are key requirements to improved self-management and health outcomes (Eklund et al., 2019; Garvey et al., 2021).

Feedback from those who participated in the group education sessions and reflections at the Indigenous Governance meetings showed that patients strongly valued opportunities to learn collectively with peer educators, clinicians and caregivers. It was recognised as a familiar Aboriginal learning process (Wilks et al., 2020). Barlow et al. (2005) explained that participants might express great enjoyment for collective learning, as an opportunity to share common health experiences in a reassuring, comfortable environment, and to learn from and with each other. Feedback confirmed high value and retention of knowledge from educational information delivered with images, and uncomplicated and easy-to-understand English. It is well documented that Aboriginal people have a mastery of their own First

Languages, but the persistent provision of healthcare and healthcare resources in English alienate people from effectively navigating the health system due to language and cultural barriers (Kerr et al., 2022). It was also confirmed, in field observations, that adults with ESKD who are living with related morbidity (e.g. type two diabetes, post dialysis fatigue) experience additional learning challenges to visual, auditory and cognitive processing (Torreggiani et al., 2022). However, these challenges can be overcome with show and share, teach back, Indigenous languages translation, visual learnings and voice amplifying devices, which are used throughout usual care at the NSDTP. These equity-enabling learning tools support effective and impactful delivery of health-enabling messages in a way that being culturally relevant within this patient group demonstrated mastery in how those supports were positively utilised. Both current study and broader literature suggest that these health practices demonstrate respect (Cox and Simpson, 2020; D'Antoine et al., 2019; Queensland Health, 2015). When suggestions for improvement were sought within this qualitative study, it was found that reinforcing information was helpful for those who experienced transient or memory challenges due to their change in illness and related treatment; Torreggiani et al. (2022) also support these findings.

The goal of promoting self-management is to improve self-efficacy and indirectly reduce burden on the health system; this study found that the *Live Strong* project was able to achieve this at multiple levels. Field notes suggested that service flexibility, team efforts, empathetic staff and rapport with patients were the key facilitators to this health outcome. Furthermore, COVID-safe education sessions assisted dialysis patients to be safe during the pandemic, which was crucial, as patients with kidney failure were more susceptible to COVID-19 transmission and infections





due to low immunity (El Karoui and De Vriese, 2022). These findings confirm that coordinated, respectful, tailored and flexible care can prevent avoidable hospital admissions and improve patient health outcomes (Battersby et al., 2010; Eklund et al., 2019), as was demonstrated by the *Live Strong* project.

While the *Live Strong* project and related staff received positive feedback from participants, the study findings suggested that when asked to provide suggestions to improve care, patients recommended that the broader health system needed to strengthen cultural understanding and support patient health beliefs. Overt and covert racism are experienced by Aboriginal and Torres Strait Islander people in all parts of life, including within healthcare settings, which are proven determinants of poor health and wellbeing (Falls and Anderson, 2022). Patient and caregiver feedback suggested that such incidents perpetuated mistrust and disrespect towards the overall health system and hampered patients' *Live Strong* journey; therefore, more needs to be done to promote cultural safety within the broader health system (Cox and Simpson, 2020).

All patients were asked what *Live Strong* meant to them. Responses suggested that at an individual level, *Live Strong* meant building and retaining personal identities that displayed dignity, self-worth and promoted independence. The IPRG members explained that more meaningful and culturally appropriate self-management education sessions and patients' active engagement in the decision-making process could help achieve these outcomes. Literature suggests that identity, meaning and empowerment are important components of personal recovery journey (Leamy et al., 2011), and relevant to Aboriginal patients' wellbeing in their health journey transition to living (and surviving) with long-term dialysis care.

Patient participants also expressed their needs of unimpeded ability to practice their cultural traditions, beliefs and values. Their feedback confirmed that the health system, family and culture all played crucial roles in how patients sought health information and care, utilised services, managed their health, and engaged with care that cumulatively supported health and wellbeing. It is acknowledged that Aboriginal and Torres Strait Islander people are inherently tied through ancient ancestral family lines to their Country (Garvey et al., 2021; Gee et al., 2014). Country is healing, and Aboriginal people and Torres Strait Islander people in turn exercise care and custodianship over Country; healing is practiced through the expression of their culture. Hence, while living with kidney failure, First Nation peoples of Australia still exercise cultural practices and strongly desire unimpeded access to their Country. This is very spiritually challenging to a person's wellbeing when physically sustaining dialysis is not accessible on their Country. These findings explain *Live Strong* project's value proposition, which was strongly supported by patient perspective.

### Study strengths and limitations

It is acknowledged that phone interviews were used to gain feedback from patients and caregivers, and were utilised in preference to focus groups, which were not permitted due to the Public Health Directive in place at that time of the research and evaluation cycle (Figure 1). The telephone interviews were likely to underestimate strength of observational feedback from participant facial expressions, body language and interactions.

There were several strengths of the study. The design and implementation of three service innovations was intentionally strengths-based according to an Aboriginal health worldview, and these principles carried into the research evaluation. Best research practice for culturally appropriate qualitative research





conduct was incorporated, consistent with recommendations by [D'Antoine et al. \(2019\)](#) and by a different government-funded health provider than the setting of this health service innovation ([Queensland Health, 2015](#)). During the study period (2021–2022), important and urgent patient feedback was always relayed back to the clinicians and hospital management through pre-established usual care governance processes. This ensured uninterrupted patient safety and care optimisation.

The project employed research staff who accepted clinical-cultural-research mentoring as needed for their roles; patient feedback reflected that delivery of those innovative services by the healthcare team demonstrated staff capability to provide professional high-quality healthcare with respect, empathy and supported patients' goals-based care. Overall, this study demonstrated that Aboriginal and Torres Strait Islander people, as patients and health professionals, successfully led and delivered a culturally respectful model of care in a challenging time (COVID-19 pandemic). This provides evidence and encouragement of future approaches to design, implement and evaluate service innovations as often as are needed ([Supplementary File S2](#)).

## Conclusions

The qualitative evaluation of the *Live Strong* project confirmed that participants regarded all three service activities implemented within the COVID-pandemic as effective and culturally safe. Patients who experienced both immune-suppression and frailty due to kidney failure highly valued the services. Findings confirmed that patients gained knowledge and demonstrated capability in kidney health optimisation, self-management and self-advocacy. The pre-existing healthcare program (NSDTP) demonstrated a capacity to integrate additional services that were valuable to

both patients and the healthcare team, and to position Aboriginal and Torres Strait Islander people's self-determination to achieve considerable health gains.

## Author contributions

This paper was led by S.Z. and J.T.H., who prepared the first draft. All other authors made substantial contributions to study design, data acquisition, analysis or data interpretation. All authors approved the final version of the paper before submission.

## Data statement

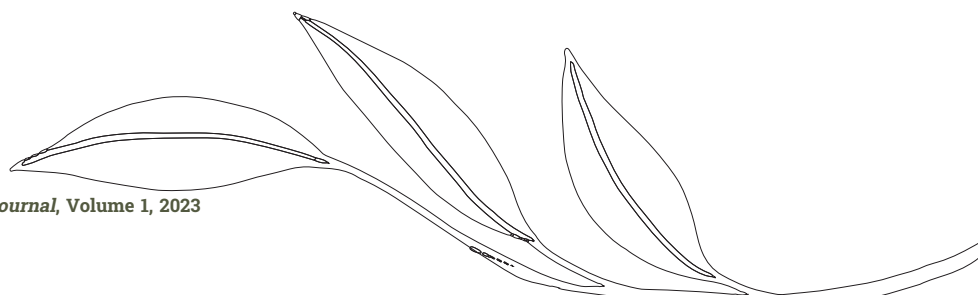
The project was developed from First Nation peoples wisdom, specific for this Country (Top End of the Northern Territory), and this project. The raw data is therefore not authorized for sharing, however we have shared our learning, as encouragement and wisdom for other communities striving for health improvement.

## Declaration of interests

S.Z., R.M. and J.T.H. report that administrative support was provided by the Menzies School of Health Research and Flinders University Northern Territory. J.T.H. reports that administrative support was provided by Northern Territory Top End Health Service (TEHS). Except for S.Z., A.M.E. and four IPRG members, the others are/were employed by the Northern Territory Top End Health Services (TEHS), where the project took place.

## Funding

The study was funded by APPRISE-Ramsay First Nations COVID-19 grant and Northern Territory Health. The research activity was delivered by clinical staff of Top End Renal Services (TERS), and research staff of Menzies School of Health Research and Northern Territory Flinders University. R.M. and S.Z. were supported by APPRISE-Ramsay First Nations COVID-19 grant. J.T.H. was supported by NHMRC Fellowship 1174758. The project was delivered by clinical staff of





Top End Renal Services (TERS), and research staff of Menzies School of Health Research and Flinders University Rural and Remote Health (NT).

### Acknowledgements

The authors acknowledge colleagues from Top End Renal Services (TERS) for the work they do to improve outcomes for patients, for clinical governance in delivery of this project and all patients who are partners in their care. This research study was initiated at, and supported by, the Menzies School of Health Research, and supported by other study partners including Top End Health Services (TEHS), Northern Territory Health and Flinders University.

### Indigenous data sovereignty

Indigenous Data Sovereignty refers to the use of health data by Aboriginal and Torres Strait Islander peoples as individual and collective of their represented Nations. This process helps to understand their own health journeys, through their own data that remain within the ownership of Aboriginal and Torres Strait Islander people, even when licensed to a health service provider. As an adjunct to Aboriginal and Torres Strait Islander peoples' millennia of ancestral knowledge, the collaboration between patients and clinicians informed the design of the NSDTP, demonstrating actions of Indigenous Data Sovereignty. The authors acknowledge that this study-related Indigenous cultural and intellectual property remains within the ownership of Aboriginal and Torres Strait Islander peoples.

### Author biography

**Sara Zabeen** is a Bangladeshi woman who has also called Australia home since 2012. She is a public health professional, with over seven years' experience as a health researcher. Her topic of interests and research expertise include chronic condition self-management, integrated care, Indigenous health and wellbeing, and

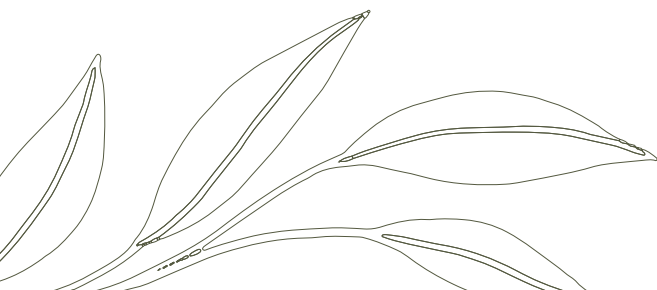
implementation science. Ms Zabeen believes in health equity and social justice and works accordingly.

**Anne-Marie Eades** is a Noongar woman from WA and a descendant of a Willman father and Minang mother. Dr Eades' research interests relate to the role of psychosocial factors in chronic disease and building resilience in Aboriginal and Torres Strait Islander health. She has a particular interest in women's issues and children in out-of-home care. Dr Eades has a background in Nursing and her PhD study was understanding how individual, family and societal influences impact on Indigenous women's health.

**Onika Paolucci** is a proud descendant of Muran/Iwaidja people from Minjilang country West Arnhem Land. She is an Aboriginal and Torres Strait Islander Health Practitioner in renal care since 2019. She is passionate about empowering mob through knowledge sharing about kidneys in a culturally respectful and culturally safe way.

**Richard Modderman** was a senior physiotherapist employed by Royal Darwin Hospital during this project to deliver the Frailty to Fit pilot innovation that was evaluated in this research. Mr Modderman is also an associate lecturer at Flinders University in Darwin, Northern Territory. His research involvement has focused on translational approaches for improving clinical practice and person-centered care through physiotherapy, including the spectrum of emergency care through to chronic disease management. He has particular interest in patient-important management of frailty in people with chronic kidney disease, and the value of multidisciplinary care in sustainable healthcare reform.

**Clee Tonkin** is a senior physiotherapist with 12 years' experience working at Royal Darwin Hospital, Northern





Territory Department of Health (Darwin, Northern Territory, Australia). Clee is passionate about providing individualised patient-important care with particular focus on improving access to quality physiotherapy care for Aboriginal and Torres Strait Island people.

**Kerry Dole** has 29 years of clinical nursing experience, with 24 of those years being in renal nursing. She commenced her renal career in the United Kingdom, moving to Central Australia in 1998, then to the Top End Renal Service in 2006 and relocating back to Central Australia in 2022. Kerry has demonstrated compassion and commitment to renal nursing, especially in the field of kidney transplant, raising the profile of kidney transplant in the Northern Territory and improving access to kidney transplant for all Territorians, especially Indigenous Australians. Kerry has authored and co-authored publications relating to kidney transplant in the Northern Territory.

**Gwendoline Lowah** is a Torres Strait Islander woman, living and working on Larrakia Country (Darwin, Northern Territory, Australia). Ms Lowah is a Clinical Nurse Consultant supporting dialysis access and provision at Royal Darwin Hospital dialysis unit.

**Kirsty Annesley** is the Director of Financial Modelling. She is based on the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Kirsty leads a dedicated and compassionate team that promotes value-based care in the Northern Territory. She has a deep understanding of Australian Indigenous health needs and works accordingly to fulfill them.

**Jacqueline Kent** is the Senior Health Information Manager of the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern

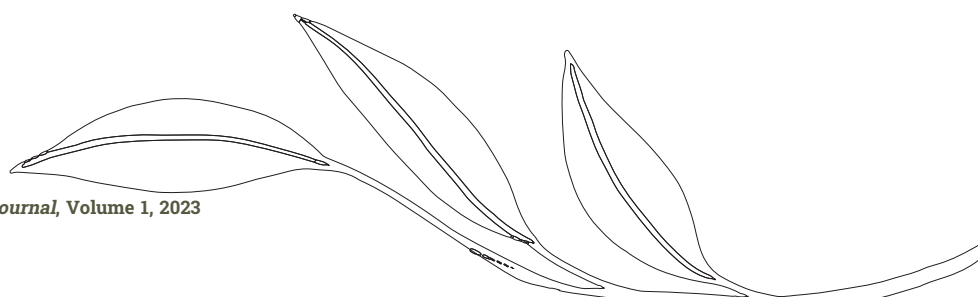
Territory, Australia). Jackie is an experienced health professional who stresses importance on improving the social determinants of health. She has a great understanding of the socio-environmental factors that influence the health seeking behaviours of Aboriginal and Torres Strait Island patients.

**Emidio Coccetti** is the Business Systems Analyst, Division of Medicine Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Emidio has over 15 years' experience in working with Department of Health data and information.

**Anne Weldon** is working as the Data Improvement Analyst in the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Anne is an empathetic and passionate health professional who pays special focus on how to improve the service recordings within the system.

**Anne-Marie Puruntatameri** is a Tiwi Elder woman. She has been a leader in clinical research partnerships, which informed this collaboration, and recently served as Chairperson of the Top End Health Service Renal Indigenous Patient Reference Group (2019–2021). She holds a Diploma in Aboriginal Health, and is now retired from her role as Aboriginal Health Practitioner in the Tiwi Islands. She is also involved in a range of community works - alcohol, diabetes, and kidney awareness program. Anne-Marie also raises awareness about the need of nutrition and COVID-safety in the remote area.

**Edna May Wittkopp** is a Goba woman from Moa Island (Torres Strait Island, Queensland, Australia), living on Larrakia Country, Northern Territory, Australia. She is an educator and interpreter. Ms Wittkopp completed certificate III in Business Administration. In the past, she worked for Northern Territory Health as



an administrative officer. Before retirement, she was working with Australia Post.

**Wayne Alum** belongs to the Jingli tribe (Darwin, Northern Territory, Australia) and considers himself a community role model. He has 16 years' work experience with the Mission Australia as a Community Service Worker. He also worked six years as a Medical Transport Officer with the Northern Territory Health Service. He is a trainer, educator and supervisor. Mr Alum also supports his community people with housing and mental illness issues. He has obtained certificates on Suicide Prevention and Alcohol and other Drugs.

**Tolbert Dharromanba Gaykamangu** is a Gapuwiyak leader (Ramingining, Northern Territory, Australia) and an artist. He is the vice-chairman of the local art centre. In Darwin, he teaches and encourages his renal hostel peers about COVID-safe practices, good ways and right ways (to live), and healthy lifestyle for renal patients (e.g. walking). Mr Gaykamangu obtained a certificate on art from the Darwin Museum and completed a computer course from the Charles Darwin University.

**Jaquelyne T. Hughes** is a Torres Strait Islander woman (Wagadagam tribe), a nephrologist and clinician researcher, mentor, and Indigenous Health Systems Innovator based on Larrakia Country (Darwin, Northern Territory, Australia).

### Supplementary material

Supplementary material associated with this article can be found in the online version at [10.1016/j.fnhli.2023.100001](https://doi.org/10.1016/j.fnhli.2023.100001).

### References

- Barlow, J.H., Bancroft, G.V., Turner, A.P., 2005. Self-management training for people with chronic disease: a shared learning experience. *J. Health. Psychol.* 10 (6), 863–872. <https://doi.org/10.1177/1359105305057320>.
- Battersby, M., Von Korff, M., Schaefer, J., Davis, C., Ludman, E., Greene, S.M., Parkerton, M., Wagner, E.H., 2010. Twelve evidence-based principles for implementing self-management support in primary care. *Jt. Comm. J. Qual. Patient. Saf.* 36 (12), 561–570. [https://doi.org/10.1016/s1553-7250\(10\)36084-3](https://doi.org/10.1016/s1553-7250(10)36084-3).
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3 (2), 77–101. <https://www.tandfonline.com/doi/abs/10.1191/1478088706QP0630A>.
- Cangini, G., Rusolo, D., Cappuccilli, M., Donati, G., La Manna, G., 2019. Evolution of the concept of quality of life in the population in end stage renal disease. A systematic review of the literature. *Clin. Ter.* 170 (4), e301–e320. <https://doi.org/10.7417/CT.2019.2152>.
- Chun Tie, Y., Birks, M., Francis, K., 2019. Grounded theory research: A design framework for novice researchers. *SAGE. Open. Med.* 7, 2050312118822927. <https://doi.org/10.1177/2050312118822927>.
- Corbin, J.M., Strauss, A., 1990. Grounded theory research: Procedures, canons, and evaluative criteria. *Qual. Sociol.* 13 (1), 3–21. <https://link.springer.com/article/10.1007/bf00988593>.
- Cox, J.L., Simpson, M.D., 2020. Cultural Humility: A Proposed Model for a Continuing Professional Development Program. *Pharmacy.* 8 (4), 214. <https://doi.org/10.3390/pharmacy8040214>.
- D'Antoine, H., Abbott, P., Sherwood, J., Wright, M., Bond, C., Dowling, C., Bessarab, D., 2019. A collaborative yarn on qualitative health research with Aboriginal communities. *Australian Indigenous Health Bulletin.* 19 (2), 1–7. <https://healthbulletin.org.au/articles/a-collaborative-yarn-on-qualitative-health-research-with-aboriginal-communities>.
- Datta, R., 2018. Traditional storytelling: An effective Indigenous research methodology and its implications for environmental research. *AlterNative.* 14 (1), 35–44. <https://doi.org/10.1177/1177180117741351>.
- Eklund, J.H., Holmström, I.K., Kumlin, T., Kaminsky, E., Skoglund, K., Högländer, J., Sundler, A.J., Condén, E., Meranius, M.S., 2019. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient. Educ. Couns.* 102 (1), 3–11. <https://doi.org/10.1016/j.pec.2018.08.029>.



- El Karoui, K., De Vriese, A.S., 2022. COVID-19 in dialysis: clinical impact, immune response, prevention and treatment. *Kidney Int.* <https://doi.org/10.1016/j.kint.2022.01.022>.
- Falls, T., Anderson, J., 2022. Attitudes towards Aboriginal and Torres Strait Islander peoples in Australia: a systematic review. *Aust. J. Psychol.* 74 (1), 2039043. <https://doi.org/10.1080/00049530.2022.2039043>.
- Garvey, G., Anderson, K., Gall, A., Butler, T.L., Whop, L.J., Arley, B., Cunningham, J., Dickson, M., Cass, A., Ratcliffe, J., 2021. The fabric of Aboriginal and Torres Strait Islander wellbeing: a conceptual model. *Int. J. Environ. Res. Public Health.* 18 (15), 7745. <https://doi.org/10.3390/ijerph18157745>.
- Gee, G., Dudgeon, P., Schultz, C., Hart, A., Kelly, K., 2014. Aboriginal and Torres Strait Islander social and emotional wellbeing. In: Dudgeon, P., Milroy, H., Walker, R. (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. Commonwealth of Australia, pp. 55–68. [https://d1wqtxts1xzle7.cloudfront.net/34654727/Working\\_Together\\_Book-libre.pdf](https://d1wqtxts1xzle7.cloudfront.net/34654727/Working_Together_Book-libre.pdf).
- Gentles, S.J., Charles, C., Ploeg, J., McKibbin, K.A., 2015. Sampling in qualitative research: Insights from an overview of the methods literature. *Qual. Rep.* 20 (11), 1772–1789. <https://doi.org/10.46743/2160-3715/2015.2373>.
- Hughes, J.T., Dembski, L., Kerrigan, V., Majoni, S.W., Lawton, P., Cass, A., 2018. Gathering Perspectives - Finding Solutions for Chronic and End Stage Kidney Disease. *Nephrology.* 23 (Suppl 1), 5–13. <https://onlinelibrary.wiley.com/doi/full/10.1111/nep.13233>.
- Hughes, J.T., Freeman, N., Beaton, B., Puruntatmeri, A.-M., Hausin, M., Tipiloura, G., Wood, P., Signal, S., Majoni, S.W., Cass, A., 2019a. My experiences with kidney care: a qualitative study of adults in the Northern Territory of Australia living with chronic kidney disease, dialysis and transplantation. *PloS one.* 14 (12), e0225722. <https://doi.org/10.1371/journal.pone.0225722>.
- Hughes, J.T., Kirkham, R., Min, O.A., Hall, H., Currie, B., Majoni, S.W., 2019b. Patient-identified health service transformation: an Aboriginal patient's experience with extensive chronic tinea corporis and delayed kidney transplantation wait-listing. *Ren. Soc. Australas. J.* 15 (3), 92–96. <https://search.informit.org/doi/abs/10.3316/informit.756168943951197>.
- Hughes, J.T., Majoni, S.W., Barzi, F., Harris, T.M., Signal, S., Lowah, G., Kapojos, J., Abeyaratne, A., Sundaram, M., Goldrick, P., 2019c. Incident haemodialysis and outcomes in the Top End of Australia. *Aust. Health Rev.* 44 (2), 234–240. <https://doi.org/10.1071/AH18230>.
- Kerr, M., Evangelidis, N., Abbott, P., Craig, J.C., Dickson, M., Scholes-Robertson, N., Sinka, V., Vastani, R.T., Widders, K., Stephens, J., 2022. Indigenous peoples' perspectives of living with chronic kidney disease: systematic review of qualitative studies. *Kidney. Int.* 102 (4), 720–727. <https://doi.org/10.1016/j.kint.2022.05.030>.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., Slade, M., 2011. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br. J. Psychiatry.* 199 (6), 445–452. <https://doi.org/10.1192/bjp.bp.110.083733>.
- Mills, J., Birks, M., 2014. *Qualitative Methodology: A Practical Guide*. Sage. <https://digital.casalini.it/9781446296714>.
- Pope, C., Mays, N., 2020. *Qualitative Research In Health Care*. Wiley Online Library. <https://onlinelibrary.wiley.com/doi/pdf/10.1002/9781119410867>.
- Queensland Health, 2015. Aboriginal and Torres Strait Islander cultural capability, Queensland Health Cultural Capability Team Retrieved from [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0021/151923/communicating.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0021/151923/communicating.pdf).
- Scholes-Robertson, N., Gutman, T., Howell, M., Craig, J.C., Chalmers, R., Tong, A., 2022. Patients' perspectives on access to dialysis and kidney transplantation in rural communities in Australia. *Kidney. Int. Rep.* 7 (3), 591–600. <https://doi.org/10.1016/j.ekir.2021.11.010>.
- Torreggiani, M., Fois, A., Chatrenet, A., Nielsen, L., Gendrot, L., Longhitano, E., Lecointre, L., Garcia, C., Breuer, C., Mazé, B., 2022. Incremental and personalized hemodialysis start: a new standard of care. *Kidney. Int. Rep.* 7 (5), 1049–1061. <https://doi.org/10.1016/j.ekir.2022.02.010>.
- Wilks, J., Dwyer, A., Wooltorton, S., Guenther, J., 2020. 'We got a different way of learning': A message to the sector from Aboriginal students living and studying in remote communities. *Aust. Univ. Rev.* 62 (2), 25–38. [https://researchonline.nd.edu.au/nulungu\\_article/15/](https://researchonline.nd.edu.au/nulungu_article/15/).

