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Incorporating indigenous knowledge in health services: a consumer partnership framework



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ABSTRACT

Objectives: Healthcare policy and planning should be informed by a partnership between healthcare services and healthcare users. This is critical for people who access care frequently such as indigenous Australians who have a high burden of chronic kidney disease. This study aimed to explore the most appropriate ways of enhancing services by incorporating renal patients' expectations and satisfaction of care in Australia's Northern Territory.

Study design: This is a participatory action research.

Methods: Six aboriginal health users with end-stage kidney disease were recruited to form an Indigenous Reference Group. This group met bimonthly between April and November 2017 and meetings took the same structure as a focus group. Findings from these meetings were presented to health policy and planners in a feedback loop implemented by the study.

Results: This framework enabled indigenous knowledge to guide the project, indigenous priorities to be identified in this context and timely feedback of information to inform the strengths and priorities of the health service. Changes were recognised and addressed immediately.

Conclusions: This qualitative research framework is a useful mechanism for providing local data to inform patient-centred health system change as expressed by health users. We recommend this consumer partnership framework be embedded into existing operational structures to support the ongoing sustainability of this group.

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It is an Australian priority, expressed through agreed National Quality and Safety Health Service Standards, that healthcare services partner with health care users to inform the design and delivery of safe and high-quality health care.^{1,2} This commitment is critical for indigenous people who have a holistic view of health, in the context of self, community and country, and health services that have traditionally siloed care within subspecialty clinical domains.

Indigenous Australians have a heavy burden of dialysis-dependent end-stage kidney disease (ESKD), occurring at earlier ages than other Australians, and disproportionately affecting socio-economically disadvantaged people³ and people living in remote regions.^{4,5} Causes of this include, but are not limited to, low birthweight, diabetes, hypertension, glomerulonephritis and socio-economic disadvantage.

The Northern Territory (NT) has a dispersed population of 244,000 people⁶ living in an area of 1.42 million km². Nephrology services are coordinated from the central hubs in the regional centres of Darwin in the Top End and Alice Springs in Central Australia and provide care for a population with the highest national incidence of ESKD requiring dialysis.⁷ Patients relocating from remote areas to access care also face challenges of negotiating the health system, securing housing and English as a second (or subsequent) language, while maintaining commitments to family and culture.⁸

The Top End Health Service (TEHS) spans 35% of the NT land area, supporting hospital care in Darwin, East Arnhem and Katherine regions and 36 primary healthcare facilities.⁹ In 2016–2017, the TEHS supported 77,534 admissions for haemodialysis treatments.⁹ This service recognises the need to enhance services to align with the needs of clients and to enhance efforts to prevent the development and progression of chronic kidney disease. As such, it recently embarked on projects aimed at optimising the integration of health care across specialist services (centrally based in Darwin) and primary healthcare services (located in urban, regional and remote sites). One goal of the integration project was to determine the range of experiences and satisfaction of patients using renal care services. Obtaining healthcare user feedback would also inform the appropriateness of developing longitudinal survey instruments to record changes.

Preliminary investigation by the TEHS identified quantitative survey instruments developed in other healthcare settings with different demographic and healthcare needs. However, the TEHS recognised that a tool needs to be relevant to the context and invited a collaborative research partnership to develop an appropriate methodology, lead the data acquisition and analysis phases and cointerpret the findings. The investigator team decided that an exploratory work was required to understand the main constructs relevant to a survey tool, which involved the following: the development of a framework that prioritised indigenous voices, enabled the timely validation of findings and provided a mechanism for feedback between stakeholder groups.

We describe the methodological framework developed to optimise the qualitative feedback from indigenous patients (the study's indigenous patient reference group [IRG]) using

renal services for the My Experiences and Satisfaction with Kidney Care (ME & Kidney Care) project.

Framework development

Ethics, governance and leadership

The study was commissioned by the TEHS Renal Services Integration of Care project, and the ethical approval was gained from the Human Research Ethics Committee of the NT Department of Health and the Menzies School of Health Research (HREC 2016-2721). The TEHS funded the project and contributed a project officer (the Renal Service Indigenous Liaison Officer [ILO]). The ILO was a key informant on context-specific protocols in the project development phase and enhanced community engagement. Menzies contributed researchers (qualitative and clinician), and both groups contributed to the study leadership and governance.

Indigenous reference group

A participatory action research framework was used. The IRG was formed at the outset to identify patient's priorities, provide feedback and guide study processes (including recruitment strategies, interpretation of findings and dissemination of results). IRG meetings were structured as a focus group, whereby the research team had a broad interview guide based on emerging findings from previous discussions, as well as interviews and case studies that were informing the wider study.

Aboriginal patients requiring maintenance haemodialysis who resided in Darwin were invited by the ILO to be the members of the Indigenous Reference Group, following a 1-month period of advertising and expression of interest. Six patients agreed to be involved (four females, two males, age range 58–74 years). Most members were not well acquainted with each other, had diverse renal experiences and were from different Top End regions. The members of the IRG met bimonthly (between April–November 2017), at a local renal service (once) and the research institute. Meeting times were scheduled on a non-dialysis day; participants were provided with light refreshments (as approved by a renal dietician) and transport facility. Duration of the meetings was approximately 2 h, and the participants were reimbursed for their time. Each meeting was audio recorded, transcribed and deductively analysed by the research team following up each focus group.

A direct feedback loop to health services management responsible for policy and planning was established (Fig. 1). At each of the IRG meetings, findings from the previous focus group were presented, and interpretation was cross checked for accuracy. This process enhanced rigour and provided continual opportunities for reflexivity. These findings were then presented to the health service leadership (the investigator meeting and renal services integration project steering committee). Two IRG members were invited to attend the bimonthly investigator meetings, participating in sharing emerging findings and ensuring accountability of the research team.

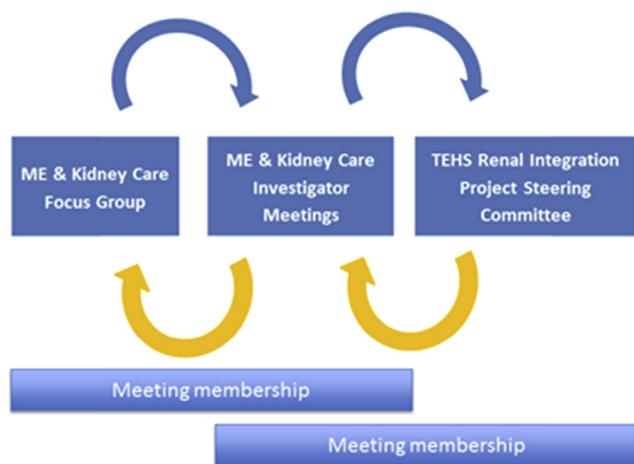


Fig. 1 – Methods informing feedback to health service. ME & Kidney Care, My Experiences and Satisfaction with Kidney Care; TEHS, Top End Health Service.

Findings

Working respectfully with aboriginal and Torres Strait Islander people

The study aligned with the Australian National Health and Medical Research Council guidelines for working respectfully with Aboriginal and Torres Strait Islander people.¹⁰ These principles focus on the values of spirit and integrity, reciprocity, respect, equality, survival and protection and responsibility. Specifically, the framework enabled indigenous knowledge to guide the project by regularly providing feedback, identifying indigenous priorities in this context and providing recommendations for the ongoing sustainability of this group. Indigenous Reference Group members were highly supportive of this health service's work, actively engaged and strong advocates for patients. A common discourse among IRG members was around the importance of the group:

I mean what is important about this group is [...] we have experience with the participation of real doctors, kidney specialists and nurses [...] And I hope that out of this group that something is taken seriously for the future for other renal patients.

An emerging issue was that ESKD patients desire opportunities to positively influence renal care policies. The IRG provided a positive structure for those involved. Two-way reciprocity included specific knowledge enhancement of IRG members on biomedical aspects of kidney diseases and the processes underpinning effective health system policy development. The study also provided a professional capacity building opportunity to the health service. Specifically, the ILO was supported in a project leadership role and trained in qualitative research methods.

A responsive health service

The consumer partnership framework enabled timely feedback to inform the strengths and priorities of the health

service. Changes were recognised and addressed immediately, before formal analysis of all data. Some practical examples include identifying unmet needs of remote patients at the time of haemodialysis initiation.

Some of the countrymen are scared. When I started dialysis I didn't know what was going on to tell you the truth. I didn't know who to talk to, where to go.

In response, the TEHS has operationalised the 'Kidney Yarning Circle-Pathways to My Home' education programme to assist with providing appropriate information and orientation to services. Additionally, concerns were raised about inefficiencies of the renal transport system and appropriateness of hostel (accommodation) protocols:

We got to live freely, not somewhere like for instance the hostel, where you live in the compound.

They [patient, transport, hostel and the dialysis unit] need to sit down together and fix what times to be picked up, what times to be dropped off, what time the cage [hostel compound] should be open.

These concerns were reported to impact patient well-being. This has contributed to the action from representatives of the Renal Services Integration Project.

Importance of stakeholder participation

Meaningful participation of stakeholders is fundamental to health policy development and programme planning. This framework provided opportunities for information to be shared in a non-threatening way and has been critical to inform recommendations for obtaining patient satisfaction and experiences with health care in this setting. The health service has been respectful and responsive to processes involving partnering with consumers to reflect on activities and outcomes. Adopting a qualitative methodology that prioritises indigenous ontologies, leadership and values was critical to informing this work.

The qualitative research framework, adapted to the local context with a direct feedback loop to key stakeholders, is a valuable mechanism for providing local data to inform patient-centred health system change as expressed by health users. Indigenous Reference Group members and project investigators recognise the value of the methodology and recommend the consumer partnership framework be embedded into the TEHS operational structures. Beyond the research project, this could be achieved through providing support to establish clear terms of reference for the TEHS and key stakeholders; strong co-chairing to assist reaching consensus on key priorities; develop protocols and support wider consumer feedback (including opportunities for IRG members to disseminate information among their regional communities). In conclusion, we present a practical and effective methodology to support healthcare services to partner with healthcare users to inform the design, delivery and prioritisation of safe and high-quality health care. This approach has the potential to improve the cultural

competence of health services to better meet the broader socio-economic and cultural needs of clients.

Author statements

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Ethical approval

The ethical approval was gained from the Human Research Ethics Committee of the NT Department of Health and the Menzies School of Health Research (HREC 2016–2721).

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Competing interests

The project sponsor was the Top End Health Service, who did not influence data acquisition and analysis undertaken by qualitative researchers (R.K. and N.F.).

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