



Indigenous Patient Voices

Gathering Perspectives - Finding Solutions
for Chronic and End Stage Kidney Disease

2017 Symposium Report



In the spirit of respect, Menzies School of Health Research acknowledges the people and elders of the Aboriginal and Torres Strait Islander nations who are the traditional owners of the land and seas of Australia.

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The experiences reported by expert-patients within the Indigenous Patient Voices Symposium remain the property of each individual and have been interpreted and synthesised, with their permission, to highlight areas for health services reforms. The authors gratefully acknowledge the assistance and support of Ms Vicki Kerrigan for video reporting, and Helen Orrs Photography in the creation of this publication.

This report is useful for Australian healthcare users, the healthcare workforce, policymakers and funders of Australian health services.

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Links to external coverage of this meeting are found here

https://www.menzies.edu.au/page/Research/Projects/Kidney/Indigenous_Patient_Voices/

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Introduction

New health technologies, diagnostic and therapeutic capabilities are continually being developed and implemented, along with constant reform of the supporting health services and systems. It is critical that health services understand how health care users perceive services and if services are fit for purpose. All Australians can contribute to health care design and support change to improve health service delivery. Changes in health care delivery or health care reforms should at the outset document the rationale for change, how and in what way services will change, the measurements that will be used to determine that change has occurred, how a successful outcome will be defined, and which parties were included and excluded from the consultation and change process.

The Australian Commission on Safety and Quality in Health Care (ACSQHC) was established in 2006 by the Australian, state and territory governments to lead and coordinate national improvements in safety and quality in health care. In 2011, Health Ministers endorsed ten National Safety and Quality Health Service (NSQHS) standards which were identified by the ACSQHC in order to drive the implementation of safety and quality systems and standards of health care across Australia¹. Partnering with consumers is one of the NSQHS standards, and aims to ensure that consumers are engaged in the design, delivery and evaluation of healthcare systems and services, and that patients are given the opportunity to be partners in their own care. Furthermore, there is a specific emphasis within the NSQHS outlining requirements for better care for Aboriginal and Torres Strait Islander consumers of health care²:

1. Setting safety and quality goals for Aboriginal and Torres Strait Islander people in health service organisations
2. Cultural competency in caring for Aboriginal and Torres Strait Islander consumers
3. Improving identification rates of Aboriginal and Torres Strait Islander consumers
4. Creating safe and welcoming environments for Aboriginal and Torres Strait Islander consumers
5. Effective and safe communication with Aboriginal and Torres Strait Islander consumers
6. Comprehensive care for Aboriginal and Torres Strait Islander consumers

¹ Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards (September 2012). Sydney. ACSQHC, 2012;

² Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards, Overview: Improving care for Aboriginal and Torres Strait Islander People (October 2016). Sydney. ACSQHC, 2016.

This report documents the discussions of the inaugural “Indigenous Patient Voices: Gathering Perspectives Finding Solutions for Chronic and End-Stage Kidney Disease Symposium.”

This written report accompanies an audio-visual report (<http://bit.ly/2zBw4ol>). The priorities of health care users, the expert-patients, and carers are documented. The expert-patient delegates highlighted a number of barriers to delivering quality health services for chronic and end stage kidney disease. The feedback from expert-patients provides a clear rationale for health care reforms.

There was agreement by the non-patient-carer delegates that reforms were needed to improve access to and utilisation of health services. Key issues discussed included where and how services were provided; how health information was provided; communication processes and the makeup of the renal health care workforce.

We urge accountability of Australian state, Territory and federal government Health Ministers to this call to action. As elected members to government, Health Ministers are tasked to work closely with renal services and other key stakeholders to ensure that health services deliver high-quality, accessible and equitable care for Aboriginal and Torres Strait Islander people with chronic and end stage kidney disease. Such high-quality services should invite consumer participation and be responsive to consumer views in design, implementation and evaluation.

Delegates

<i>Patient Delegates</i>	Mr Laurie Sandy	Ms Sarah Brown	Dr Christine Kemp
Mr John Ashley	Ms Betty Tekahika	Ms Lauren Caruana	Ms Vicki Kerrigan
Mr Timothy Bidingal	Ms Toni Wanambi	Professor Alan Cass	Ms Francine Koh
Butjala	Mrs Mary Ward	Mr Craig Castillon	Dr Paul Lawton
Mr David Croker	<i>Carer- close support person delegates</i>	A/Professor John Collins	Ms Helen Mahony
Ms Dorothy Djakarni		Ms Helen Coolican	Dr Sandawana
Wubulkarra	Ms Jessie Alderson	Professor Jonathan Craig	William Majoni
Ms Gloria Friday	Ms Janet Ashley		Ms Yvonne McCauley
Mrs Maude Hastie	Ms Coralie Morgan	Ms Jenny Cutter	Professor Stephen McDonald
Mr Peter Henwood	Ms Bernadette Nunju	Mr Paul Dale	
Ms Del Hunter		Ms Urmila D'Cunha	Dr Andrew McNally
Mr Jimmy Langdon	Mrs Annette Oosen	Ms Lenore Dembski	Ms Liz Nichols
Mr David Marpiyawuy	Ms Ada Parry	Ms Kerry Dole	A/Prof Suetonia Palmer
Mr Ronno Morgan	Ms Evelyn Punguatji	Ms Donisha Duff	Ms Charmain Patrick
Mrs Aurelia Munkara	Mr Saila Savage	Ms Vicky Duff	
	Ms Sharon Ward	Dr David Fernandes	Ms Rochelle Pitt
Mrs Julie Namala	<i>Non-patient, Non-Carer delegates</i>	Dr Emma Fitzsimmons	Ms Pepita Pregelj
Ms Irene Nangala	Ms Rozhin Asghari	Mr Robert Gardos	Ms Stef Puscka
Ms Cathie Nickels	Ms Kelly Avery	Ms Talia Gutman	Ms Jennifer Robb
Mr Dunba Nunju	Dr Richard Baer	Ms Heather Hall	Dr Cherian Sajiv
Mr David Oosen	Ms Rebekah Baird	Dr Martin Howell	Dr Thwe Soh
Ms Laurencia Parmbuk	Ms Margo Bell	Dr Jaquelyne Hughes	Ms Mikaela Stafrace
Mr Victor Punguatji	Dr Amelie Bernier-Jean		A/Prof Rachael Walker
Mr Lachlan Ross		Dr Namrata Kanal	Ms Pamela Wood

Meeting purpose and agenda

Experts in kidney health, including patients and health service providers, gathered in Darwin on the 6th September 2017 and contributed to the inaugural Indigenous Patient Voices Symposium. The Symposium was a satellite meeting within the professional learning program of the 53rd Annual Scientific Meeting of the Australia and New Zealand Society of Nephrology (ANZSN). These kidney health experts comprised patient-experts, close support people or carers, and 'non-patient-carer delegates' who included a diverse range of the nephrology and primary health care medical and allied workforce, researchers and policy leaders. Representatives of the meeting sponsors – Kidney Health Australia, Novartis Australia and Astellas Pharma – also attended.

Role of meeting sponsors

The meeting was sponsored by a third-party sponsorship arrangement with industry, Astellas Pharmaceutical and Novartis Australia, Baxter coordinated through Kidney Health Australia. Funding for the full cost of the meeting (\$40,000), which enabled interstate patient and carer delegates to attend, was secured on the 3 August 2017. Sponsors did not contribute to the meeting program or contribute to the writing of this report, and senior sponsor representatives participated in the symposium as other non-patient non-carer delegates.

Selection of patient and carer delegates

Haemodialysis is the predominant treatment available to support Australians with end-stage kidney disease, but particularly for Aboriginal and Torres Strait Islander peoples. Patients and clinicians recognise that frequent regular dialysis is critical for good health, thus securing regular haemodialysis whilst travelling is necessary. Several factors were critical for the successful hosting of the Symposium, and enabling patients to attend. This included external sponsorship for accommodation and transport of local and interstate patient and carer delegates and the availability and coordination of haemodialysis treatments for non-local delegates in Darwin.

Patient-delegates were Aboriginal and Torres Strait Islander peoples, who were currently receiving supervised care by a nephrologist, and lived in the regions of the Top-End and Central Australia of the Northern Territory, Cairns and Hinterland and Thursday Island of northern Queensland, and the Kimberley region of Western Australia. Invitations were encouraged across the spectrum of chronic kidney disease, haemodialysis (nurse-assisted in a regional, remote or urban satellite unit), peritoneal dialysis, home haemodialysis and transplantation.

Kidney Health Australia supported the identification of patient participants from Queensland and Western Australia. In the Northern Territory, patient-delegates were identified and supported to attend from Central Australia by Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) and the Top-End Renal Service in the Top-End Northern Territory area, and through clinician local networks. Patient delegates travelling from outside Darwin were offered funding to enable a carer or close support person to travel with them.

Selection of clinical and policy delegates

An email was distributed to key delegates attending the Annual Scientific Meeting, targeting senior nephrology clinicians, policy makers and researchers. Within the Darwin area, the invitation was also extended to primary health care staff and specialist renal health care workers. There was an open invitation during the ANZSN ASM conference for delegates to attend. Non-patient and non-carer delegates were invited to participate in the after-lunch sessions, which enabled the patient and carer delegates to meet and discretely discuss their priorities that they wished to communicate.

Selection and role of the meeting facilitator

The facilitator was required to be an Aboriginal or Torres Strait Islander person, who had experience in meeting design and facilitation, an understanding of health and Indigenous cultures, and was available to work with the meeting organisers to design a program that would achieve the desired meeting goals. The Indigenous Patient Voices symposium brief was to facilitate a culturally appropriate shared learning session that would enable patients and carers to contribute their experiences of kidney-related health care with a non-patient non-carer audience. Over a period of six months, several facilitators were considered.

The symposium facilitator, Ms Lenore Dembski, was engaged on the 4th August 2017 following confirmation of funding. The facilitator is a senior Aboriginal woman from the local Darwin area, a business woman and a meeting facilitator. Other skills included cross-cultural training and certification, and previous experience in senior government department positions. Ms Dembski had been commissioned in October 2016 by the Annual Scientific Meeting (ASM) local organising committee for a separate ASM task (to deliver locally produced conference bags which were elaborated with Indigenous bush foods designed by Indigenous artists, and were compact and recyclable and had a low environmental footprint). Therefore over 12 months, the facilitator and meeting organisers had developed a shared understanding of the ANZSN Annual Scientific Meeting, attended by almost 500 delegates from Australia, New Zealand and South-East Asia, and the desired outcomes for the Indigenous Patient Voices Symposium.

The facilitator was given creative licence to develop the symposium program in order to achieve the brief. The facilitator used her local network to identify an Indigenous artist (Ms June Mills of Larrakia Nation Arts) to design the Indigenous Patient Voices Symposium logo and screen-print onto delegate t-shirts.

Meeting program

The facilitator engaged regularly throughout the day with expert-patient and carer delegates to ensure all who wanted to share at the open session were given the opportunity to do so. Owing to usual haemodialysis schedules, patient-related fatigue or other factors, additional patients joined or others departed after the symposium morning tea.

Table 1 Advertised and actual timetable of events

	Advertised Program	Symposium Timetable*
0800-0830	Registration	Registration (extended to 0930)
0830-1030	Patients and Carers yarnning circle (closed meeting: clinicians and policy makers were not invited)	
	Welcome to country	
	Introductions	
	Sharing Stories	
	Understanding common themes (facilitated)	
	Agreement for presentations at next session	
10.30-11.30	Brunch	
11.30-13.00	Presentation by patients and/or carers (open to all delegates)	
13.00-13.30	Lunch	
13.30-15.00	Facilitated discussion of themes arising from patient/carers presentations, with clinician and policy maker input	Presentation by patients and/or carers (open to all delegates)
15.00-15.30	Afternoon tea	
15.30-17.00	Facilitated “solutions and brainstorming” discussion (all involved)	Facilitated discussion of themes arising from patient/carers presentations, with clinician and policy maker input
17.00-17.30	Travel to Parliament House	
17.30-19.00	Parliamentary reception with NT Minister of Health Natasha Fyles MLA	Parliamentary reception with • Mr Lawrence Costa, member for Arafura, and Assistant Minister for remote health delivery and homelands, and • Ms Sandra Nelson MLA, member for Katherine and Assistant Minister for the Prevention of Family violence & Women’s Policy. • Ms Betty Tekahiko Mabo- Indigenous Patient Voices Expert Patient representative
*Differences to advertised program indicated on the right		

This extended the timetable to ensure participation of all patients, enabling them to speak first, before seeking reflective responses from the non-patient-carer delegates. Thirty three expert-patient and carers attended the symposium, with 21 speaking openly and sharing their stories of chronic and end stage kidney disease. The facilitator did not restrict the themes or content of the expert-patient or carer feedback. In the later open sessions with non-patient-carer delegates, the facilitator asked the patient-expert speakers to share their experiences in a particular order to help draw out the emerging themes from their narratives. Expert-patients shared their experiences of living with chronic kidney disease, renal replacement therapies, and their experiences of the health care systems available to them. Patients highlighted shortcomings with service delivery, along with their proposed solutions.

While the expert-patients were sharing their experiences, the non-patient carer delegates were invited to sit and respectfully listen without interruption until the expert-patients had completed their feedback. Throughout the day, all non-patient-carer delegates were encouraged to consider their personal response to the feedback in support of the expressed priorities of Aboriginal and Torres Strait Islander health care users with kidney diseases. In the session following afternoon tea, the facilitator invited other delegates to respond and outline suggestions or ask questions about ways forward to advance patient-led priorities in kidney health.

Data analysis

The meeting with all delegates present was recorded and filmed with participant consent. Film excerpts were used to form the audio-visual report (led by Vicki Kerrigan). Consent to have their stories recorded for this purpose was gained from participants. Patients asserted that their account of their experiences, shared within the meeting, represents and will remain their own property. For the written report (led by Jaqui Hughes) the shared feedback was recorded in detailed notes and digitally recorded. Expert-patient feedback was clarified with individuals where necessary. All narratives were transcribed verbatim and thematically analysed.

History, context and patient experiences

Expert-patients introduced themselves in the following manner: “This is my name, skin-name, totems, and community, work-history, family and custodian responsibilities.” These matters of fact life experiences tell an important story of Australia’s post-colonial history and provide a base upon which to build effective systems of health care to improve health outcomes and realise health equity for people with chronic and end stage kidney disease.

Patients described key historical events that have shaped the way they live their lives. They shared experiences, both their own and from their families, of being relocated off country to settle in townships, and the removal of children from parents and families to government sponsored institutions. Within those government sponsored institutions, people described systematic bias towards limiting (or denying) their cultural practices and speaking Indigenous languages. Many were denied a post-primary school education, and employment opportunities were therefore limited due to poor educational attainment. External agencies exerted control over Aboriginal and Torres Strait Islander people’s lives through controlling their movements, income, and marriage relationships.

Patients pointed to key historical milestones, including the 1967 Australian Referendum, which included Aboriginal and Torres Strait Islander people in the national census and allowed the Commonwealth government to make laws for Aboriginal and Torres Strait Islander peoples; the successful Australian High Court Mabo decision recognising native title in Australia, which rejected the colonising ideology of Australia being nobody’s land (terra nullius); and families returning to ancestral homelands if they were able to secure Aboriginal Freehold. It was recognised that gaining access to traditional lands has not been available to all dispossessed Aboriginal and Torres Strait Islander people.

Limited access to health services and the impact of relocation

Patients and carers shared a strongly held belief that repeating the systematic forced removal of people from their homelands, in order to access health care (which has a central delivery focus), has not produced the desired health gains. They reported the heartbreak of not being able to spend more than a few days away from their dialysis unit due to the constant need for regular dialysis, and thus never seeing family or country for more than a few days at a time.

“A dialysis patient being away from home and families, is no good”

“My community is 1000km from Darwin. I’ve been on dialysis now for 3 years, and I am based here now because I have to be close to treatment.”

“We’ve got to leave our homes and come to Darwin. It’s a long way. It is a sad story. Think about it deeply, properly and seriously, because it is a serious problem.”

- Patients experienced overwhelming loneliness, distress and isolation following relocation to access dialysis services. These experiences were exacerbated by limited, restrictive and expensive accommodation options in cities where patients were accessing dialysis, and which did not permit family group support for the majority of patients.

“I live in a hostel by myself”

“I used to work a lot but now I sometimes just stay home at the hostel. I get very tired and I don’t know what to do really at home [the hostel], we don’t go out”.

“It is very expensive to live here, very expensive, and it is hard to find accommodation – you have to wait for months and months or years”

“Sometimes we have to live in the long-grass, because the hostels don’t have enough spaces, and we have to move out when they have another booking.”

“Families living in Darwin [for dialysis] are missing out on ceremonies, funerals and other important stuff”

- They shared concern over the undermining of homelands, which could be overt or shrouded in withdrawal of resourcing and infrastructure, particularly with closure of key regional towns, and with it critical primary health care services. The patients described experiences of providing key value to Australia, but this was not meaningfully recognised or supported. Examples included those delegates from regional and remote areas who on the one hand have critical roles in wealth creation, border protection, land management, cultural and world heritage site preservation, and food production; yet on the other hand, their communities have not received adequate infrastructure and resourcing to sustain this, or systems of health care to support the people living in these communities.
- Expert-patients described a pervasive and persisting experience of bias in the delivery of kidney health services. Furthermore, patients reported having no accessible, transparent and accountable mechanisms to call out the bias and have it redressed.

“If there is a process, let it be known”

“There are seven of us here now [in this town] from my community, why can’t we have a dialysis machine there now?”

“[Patients and] families from different islands [within the Torres Strait] are living in Cairns and Townsville [for dialysis] because they can’t go back; there is no [dialysis] machine]. And they cry, their tears are running, because they want to go back home, they miss their families, they miss the lifestyle of the islands, because they are islanders”.

“We need to have something done for us, like putting in dialysis machines for us there and nurses and doctors.”

“To make our lives better, they should be building facilities in more remote areas”

“It’s really important that if we have to pass away [die], it’s got to be on country.”

“We believe country heals you, gets you better.”

The Deficits

Expert-patients described several deficits including low community awareness of kidney health and chronic kidney disease, which can perpetuate future risk and burden of disease among younger generations; inadequate primary and secondary prevention strategies to inform people at risk of progressive kidney disease; the devastating impact of a late diagnosis of advanced or end stage kidney disease; numerous barriers to accessing health services; and lack of information about how renal health services operate.

Patient experts described the following deficits:

- Late diagnosis and lack of appropriate systems of information sharing within the community and primary health care environment:
 - Many expert-patients were diagnosed at a late or advanced stage of kidney disease or experienced rapidly progressive kidney disease, which had devastating impacts on them and their families.
- Health services
 - Poor access to health services, especially home- or community-based dialysis and transplantation;
 - Meaningful information sharing was poor or absent, which directly impacted on patients' and their families' ability to master their health-journeys and confidently and expertly self-care; and
 - Not being valued as a person (with consequent harms) within the health care system.
- Information and education:
 - Lack of information; and
 - Inadequacies (failure) of existing communication methods and materials for health promotion.
- Patients recognised that Indigenous members of communities were being asked to “volunteer” to provide basic health services work, but were not being recognised in these critical roles - being excluded from financial remuneration for work undertaken, and excluded from championing health care innovation, solutions and the need for accountability.

Personal impact of chronic kidney disease and current models of care

Patients described current models of care as having a biomedical focus and not being holistic. Current models of kidney care “*missed the mark*” by failing to address patient-prioritised outcomes. The reported lack of patient-centred care was discussed as a lack of respect for patients as individuals within health services which were not culturally safe. Patient-experts spoke of the vulnerability of being on the receiving end of health services which they often perceived to be uncaring, which had inbuilt punitive consequences for “non-conforming” patients.

The personal lived experiences of kidney disease included disbelief, separation and loneliness, leading to extreme distress. Patients reported having their life course determined by key people (gate keepers) who were poorly informed regarding their priorities. They recognised that a health workforce that did not include people from their own communities compounded their loneliness and inability to be understood. Even where processes for health care user feedback existed, through which patients might seek to report these experiences of care, patients expressed a lack of awareness regarding these processes.

Expert patients reported the models of health care available to them failed to address the issues of forced relocation. This included the inability to access affordable, timely visits to live in their own homes with their family (in homelands), care which did not meet the patients’ needs to be present at critical family and community events, and failure to ensure safe and suitable housing in centres where patients relocated. As a result of forced relocation, patients had diverse occupations which were forfeited following dialysis initiation. Patients reported high away-from-home living expenses, limited access to financial supports whilst managing fixed expenses. One delegate had submitted a declaration of marriage separation (for medical reasons) to Centrelink in order for his wife to continue to access support for their children.

The Solutions

Patient and carer delegates offered specific and holistic solutions at the Symposium. These solutions included improved access to healthcare in community; addressing deficits in how health care information is provided; the need for an appropriately equipped workforce. “Self-determination” was a term used by delegates to articulate processes to achieve their desired models of renal care, in partnership with Indigenous organisations. They asked for an engaged Indigenous leadership to advocate for urgent health care reforms.

Patients called for renal care close to home that must provide cultural safety and include a workforce membership from their own community. They identified the tremendous healing provided by being in their lands, in those places where they have real status as persons (as opposed to “factory line” patients). They called for a strengthened partnership with primary health care and meaningful health promotion in relation to chronic disease awareness and education. They did not believe the current models of renal care were fit for purpose, and called for external strategic partners to work together with renal services to redress this – including land councils, primary health care, elected members from their communities, local, state and national representatives and the Prime Minister.

Access to Care

- Patients recognise the bias in the health care system, such that health care systems were designed to benefit the health workforce. Equitable access to health care in places where people want to live was a strongly held solution to the current deficits in renal care delivery.

“You know, this thing with the dialysis machines and all that.....it was set up in the city and I think they sort of made it for themselves, to treat themselves (who live in cities). And we see it as Indigenous people. We have our own country out bush and we'd like it (dialysis and transplantation) to be out there with us, you know? Treating our people in our home, in our country where we belong. Safe”.

- Patients who dialyse in the community need and value access to an integrated high quality acute medical care within hospital systems when required. One delegate had successfully managed community-based peritoneal dialysis. However, when she transferred to haemodialysis, community-based care was not also available to her.

“I want it to get off the ground and have nurse supported haemodialysis at home, I would like to go home, it is better than here. I thank you all, the doctors that have helped me with the dialysis.”

- Delegates requested health services recognise vital roles of key community members who may be unable to independently self-care with dialysis, but who had critical needs to remain on country. This was a feature for everyone – the right to be able to live in their country and homes while accessing health care, but particularly highlighted for elders, and community and cultural ceremony leaders.

“We want them (the elders) to stay in communities. They are the old people; they have to hold country and family together for us. If he (my elder) has a problem, and needs an appointment (at the hospital), he can come in, but then he has to go back to our country”.

- Patients do not know who to ask for help to create a model of care that can work for them, and request such a person/ position be clearly communicated throughout the renal community, so they can engage and negotiate effectively.

“So I miss all those things, but hopefully, you know, I would have been really very happy if I had a dialysis machine there at [my community], just maybe one (machine).

I want to try to find someone or ask someone who could help me. If I could get one – just one dialysis machine to get over there in [my community] – I don't know how much it costs- and then I can have my dialysis there".

- Community initiated and partnered dialysis, with support from a regional renal hub, has been a model of care that patient-experts report to be useful and beneficial.

"I've got a good team behind me in [my regional renal support hub]. We have a good doctor and nurses behind us in the renal team - they are really good to me, and have put me on the right track."

Information

- Patients felt they were excluded from knowing how the health system works, and this limited their ability to know who to ask for help, and how to navigate the health care system. They recognised that remote communities were not provided with adequate information about accessing transplantation, and this had been transformative in key communities where such information had been provided by the community's own initiative to create renal health navigators. Patients strongly recommended health care teams identify and workshop their key health messages, to ensure the intended information is shared and can be provided in an accessible and appropriate manner that would prevent harm or offense to patients and families.

"We didn't have enough information, about how to be a living-related kidney donor, who to go to if you wanted to be a donor; the way the doctors had spoken about it with them really hurt me".

Workforce

- Patients requested **workforce enhancement across all levels of the health care team** – medical and nursing, primary health care, and health promotion and employed roles for expert-patient navigators. Strengthening primary health care staff in knowledge about kidney disease prevention, management and treatment was recommended because they are the local health workforce with general health training, but patients felt the primary health care workforce did not have sufficient skills to support an increasing population of people with diabetes and chronic kidney disease. Patients recognised the high value of qualified Indigenous renal nurses for Indigenous communities, and suggested an employment strategy to recruit, train and retain Indigenous nursing staff.
- **A culturally appropriate and communicative workforce:** The way health care workers communicate with patients was recalled with hurt and distress by some expert-patient delegates. Patients recommended that renal units evaluate their health message toolkit – do you have one, what are your key messages, with whom do you workshop and refine health messages, how do you train staff to ensure cultural safety? Are your staff sufficiently culturally-and professionally-competent to work in this workplace environment? Who is responsible for certifying this? Patients require staff to know what they are doing, and this includes cultural safety. Patients recommended the renal care workforce needs to employ and support the vital roles of health care navigators and knowledge sharers who can access remote communities, and share knowledges.

“I think there is still a lot more to be done [about workforce] out in the communities that are remote.”

Self-determination to work with our own people

- Patient [and community] voices are critical to instruct the ways ahead to create a fairer health care system for Aboriginal and Torres Strait Islander peoples with chronic and end-stage kidney disease. Patients wanted a renal workforce they can identify with, and that gives meaningful employment opportunities and pathways for Aboriginal and Torres Strait Islander people. The delegates recognised that previous governments and renal services had not responded to many requests for care close to home. Although one delegate was herself employed in the health care sector for 17 years, she was unable to receive the support she needed for her family to have community-based care.

“For nearly 10 years, I fought to have that dialysis machine in my community for him [my brother], but I didn’t have any support at all. There was no support, so he passed away, and then it was my turn to come here [to town] and have dialysis”.

“We need more consultation with the government, about getting more renal dialysis machines over there [in communities], keeping family on country, and maybe train them up on how to be on the dialysis machine, with local renal nurses to train and teach our mob to do things for ourselves.”

- Patient and carer-delegates wanted their communities to benefit from care closer to home, and recognised the value in Indigenous advocacy to assist in negotiating these desired outcomes. They recognised that Indigenous employment and training institutes were critical partners in building community knowledge and capacity to engage in a local health care workforce to enable communities:

“...to be self-determined to work with our own people”.

Engaging leadership

Patients have very clear recommendations regarding the way forward. Patients have more to offer, in terms of ongoing engagement in health services design, than the time available to them on the day of the Indigenous Patient Voices Symposium.

“So today I’m in the middle—there is a right hand, like the prime minister and the left hand, like other people, but I’m only in the middle you know. People of different nationalities or culture or countries have a different (world) view of the ways things should be. I have an important and wise worldview of the ways things should be for my family and my community, and my homelands...- the ways kidney treatments would work better”...“I’ve got other things to talk about still, but there is another thing to do now, we have to drive to meet our health minister after this at Parliament House”.

“The main message we want to send to the government is that we want to have our treatment on our own country.”



The report is supported by the
Australian and New Zealand Society of Nephrology

Call to Action

Expert-patients call upon health services and political leaders to commit to implementing reform in renal service delivery, to address the following issues over the next five years:

1. Improve the accessibility, appropriateness and quality of information about the causes, prevention, management, progression and treatment of kidney disease. Such information must take into account regional differences in culture, language, patterns of kidney health and illness, and service provision.
2. Implement and/or improve
 - a. Systems to monitor and prevent the development of chronic kidney disease;
 - b. Systems to identify and optimally manage chronic kidney disease in order to halt the progression, and avoid dialysis-dependent end stage kidney disease; and
 - c. Health service delivery audit processes to ensure activities are effective and efficient and timely in achieving the required outcomes.
3. Improve the effectiveness of communication:
 - a. Provide information regarding all modalities of treatment, including transplantation.
 - b. Provide information regarding processes of care for kidney transplantation:
 - i. Donor and recipient medical suitability criteria;
 - ii. The processes to be wait-listed for transplantation;
 - iii. The expected timeframe to achieve a decision for transplant suitability;
 - iv. The role of local nephrology units and transplanting units in kidney transplant assessment and care.
 - v. Operative and post-transplant care.
 - c. Articulate information in the most appropriate languages and formats, using accessible technologies, for the local renal patient community.
4. Redesign the Kidney Health workforce to:
 - a. Effectively provide health promotion for all people and communities, targeting primary prevention, secondary prevention and chronic and end stage kidney disease health promotion; delivered by a skilled Indigenous health promotion workforce which is supported by sufficiently resourced community-controlled comprehensive primary health care, and aided by Kidney Health specialists.

- b. Provide cultural security training, which understands, acknowledges and addresses the specific needs of Indigenous communities for that renal unit.
 - c. Provide training and employment pathways for Indigenous Australians to support the needs of people with chronic and end stage kidney disease including personal care attendants for people needing dialysis, health service navigator roles, health promotion and renal-equipped primary health care staff, and nursing and nephrologist positions.
5. Provide renal care close to home and enable all patient to access home, community and their country:
- a. Outline the processes for communities to raise and negotiate renal care partnerships so that care close to home can be safely provided for patients and families;
 - b. Support regional towns to ensure ongoing health care delivery and to ensure local accessible health care for patients and families; and
 - c. Support regional Australia transport networks and infrastructure so that the renal patient community can travel from home to treatment safely, efficiently and without exorbitant costs.
6. Building stronger services now:
- a. Design current and future renal units to provide suitable space for men's care and women's care, and incorporate design elements which value families as care givers within dialysis units.
 - b. Equip patients to master self-care in dialysis and health services navigation, in order to be more confident to take on home-based care.
 - c. Value elders and prioritise their return to community with dialysis support.
 - d. Implement regional kidney health hubs to support delivery of renal services closer to home
 - e. Reform state-wide and territory-wide dialysis tender processes, to ensure regions with high needs have a fit for purpose dialysis training and support program for patients, carers and local support staff
 - f. Create accountable workforce and process redesign options to ensure implementation of reforms to address patient priorities.
7. Health services should act now, to support repatriation of a deceased patient's body to community for burial, where the deceased patient had previously relocated to access dialysis care and not been able to die on country.



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