



title Addressing racism to improve healthcare outcomes for Aboriginal and Torres Strait Islander people: a case study in kidney care.

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Introduction

In June 2018, the Hon Ken Wyatt MP, Federal Minister for Indigenous Health, commissioned an expert panel to undertake a review of the services gaps and practical challenges faced by Aboriginal and Torres Strait Islander patients with kidney disease (Finlay and McInerney, 2018). This intervention is a consequence of the discrepancy observed in kidney care outcomes whereby Aboriginal and Torres Strait Islander people with end stage kidney disease are up to ten times less likely to receive the kidney transplant they need compared with non-Indigenous Australians (Johnson and Toy, 2017). Funding for this landmark project was provided by the Australian Department of Health under the Indigenous Australians Health Program (TSANZ, 2019).

In March 2019, the Transplantation Society of Australia and New Zealand, released the *“Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia Performance Report”* which identified “Improving the equity and accessibility of transplantation for Indigenous patients” as one of three priority recommendations for immediate implementation (TSANZ, 2019).

Action is urgently needed to address the immense health disparities in kidney disease outcomes suffered by Aboriginal and Torres Strait Islander people, who have at least six times the age-standardised incidence of end-stage kidney disease requiring treatment as non-Indigenous Australians (Anderson et al. 2008). Among adults aged 25 to 64 and people from rural and remote areas, rates are up to 15 times higher (Anderson et al., 2012; Anderson et al., 2012a). Although only 3.0% of the Australian population, around 1 in 10 patients commencing renal replacement therapy each year in Australia are Aboriginal or Torres Strait Islander people.

Despite clear and persistent evidence showing their preference for treatment at home, Aboriginal and Torres Strait Islander people have one quarter the non-Indigenous likelihood of home-based dialysis (Anderson, Cunningham et al., 2012); with one third the non-Indigenous chance of accessing a kidney transplant – one tenth if living in very remote areas (Devitt et al., 2017; Khanal et al., 2018).

Aboriginal and Torres Strait Islander peoples may experience poorer healthcare outcomes than non-Indigenous people when treated by non-Indigenous health professionals and healthcare organisations (Bourke et al., 2018; Dwyer et al., 2016). This is evident in kidney disease care, where, for example, some of the disparity to access kidney transplantation is explained by bias among non-Indigenous kidney specialists against waitlisting Aboriginal and Torres Strait Islander patients due to concerns about non-compliance (Anderson et al., 2012).

Pervasive communication failures between clinicians and Aboriginal and Torres Strait Islander patients are also likely to be a significant contributor (Anderson et al., 2008; Aspin et al., 2012, Hughes et al., 2018).

Equity in kidney care for Aboriginal and Torres Strait Islander patients should arise from work across multiple agencies to improve the ability of non-Indigenous health professionals and healthcare organisations to deliver better healthcare for Aboriginal and Torres Strait Islander people in four domains:

- **Cultural safety:** The Australian Health Practitioner Regulation Agency (AHPRA), in consultation with the leadership and advocacy of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), have carried out a program of work on cultural safety.
- **Institutional racism:** Queensland Health in partnership with the Queensland Aboriginal and Islander Health Council (QAIHC) and the Queensland Human Rights Commission (QHRC), are formally working towards reducing institutional racism (Marrie, 2017).
- **National Safety and Quality Health Service Standards:** The Australian Commission on Safety and Quality in Healthcare (ACSQH) produced the second edition of the National Safety and Quality Health Service Standards (NSQHSS) for hospital and health service accreditation, following extensive development with Aboriginal and Torres Strait Islander health leaders.

This work is underpinned by Australia's race discrimination laws, the fourth domain:

- **Race discrimination law:** Racial discrimination in the provision of health services is unlawful under Commonwealth, State and Territory discrimination law, including the Racial Discrimination Act 1975 (Cth) [RDA].

These four domains (cultural safety, institutional racism, NSQHS standards, race discrimination law) directly affect health practitioners and healthcare organisations through regulatory or quasi-regulatory approaches that begin to address the invisibility of Aboriginal and Torres Strait Islander peoples within Australian health legislation (Howse, 2011). We explore the overlaps, connections and interconnections between these domains.

Cultural safety

Regulation, or legislation, can be an effective means to drive equitable healthcare outcomes for Aboriginal and Torres Strait Islander people (Bainbridge et al., 2015). In consultation with Aboriginal and Torres Strait Islander health leaders, the Australian Health Practitioner Regulation Agency (AHPRA) have developed a definition of cultural safety:

“Cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities. Culturally safe practise is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism.” (AHPRA, 2020).

Regulatory boards and accreditation agencies will be able to use this definition to promote change by non-Indigenous health practitioners, as well as health professional education and training providers, towards better care for Aboriginal and Torres Strait Islander people.

Institutional racism

Racism is defined as a system which operates on three levels (Jones, 2000):

- internalised,
- interpersonal, and
- institutional.

Within the Australian health system, institutional racism manifests in the exclusion of Aboriginal and Torres Strait Islander people from the governance, control and accountability of health care organisations.

The significant work embarked upon by Queensland Health, with the support of QAIHC and the QHRC, is an example of an Australian jurisdiction taking steps to ameliorate institutional racism using an external monitoring and assessment

matrix composed of financial accountability, inclusion in governance, service delivery, policy implementation and employment (Marrie, 2017).

The proposed *Health Legislation Amendment Bill 2019* in Queensland will, if passed, ensure legal visibility for Aboriginal and Torres Strait Islander people within the *Hospital and Health Boards Act 2011*. South Australia, following in Queensland's footsteps, is co-designing a similar external monitoring and assessment matrix with Aboriginal people including patients, health professionals and leaders.

**National
safety and
quality
health
service
standards**

The Australian Commission on Safety and Quality in Healthcare has responded to the disadvantage Aboriginal and Torres Strait Islander people experience in accessing health services, and poorer outcomes, with six specific actions to improve healthcare organisation performance (ACSQHC, 2017).

The purpose of the standards is to re-orientate the health system to specifically meet the healthcare needs of Aboriginal and Torres Strait Islander people. The standards provide practical guidance for health service organisations, such as hospitals, to reorient to improve their service delivery to Aboriginal and Torres Strait Islander people and they are part of the triennial accreditation process for all Australian hospitals.

**Racial
discrimination
legislation**

Racial discrimination in the provision of health services is unlawful under Commonwealth, State and Territory discrimination law, including the *Racial Discrimination Act 1975* (Cth) [RDA]. These laws also prohibit forms of vilification and offensive conduct based on race, with section 18C of the RDA perhaps the best-known provision of this type.

Both direct and indirect discrimination are prohibited. Direct discrimination involves treating a person less favourably because of their race, consciously or unconsciously (for example, based on stereotyping) – it is not necessary to show an intention or motive to discriminate. Indirect discrimination involves acts and practices that may appear to treat people equally but have a disparate impact on people of a particular race and are not reasonable (Gaze and Smith, 2016).

Australian discrimination laws are focused primarily on formal equality (equality of treatment or opportunity), rather than substantive equality (equality of outcome) and target individual action that causes disadvantage, rather than societal, structural or systemic barriers (Thornton, 1990). Our laws

do not engage with broader notions of 'equity' which look to distributive justice and fairness and have an important role to play in avoiding systemic health disparities (Braveman and Gruskin, 2003). This limits the law's usefulness as a means to address the very large healthcare disparities, including kidney disease treatment, endured by Aboriginal and Torres Strait Islander people.

However, Australian laws do recognise the role of 'special measures' designed to improve the enjoyment of human rights by particular 'racial or ethnic groups' (typically those who have faced historical discrimination or disadvantage, including Aboriginal and Torres Strait Islander people). These measures are treated as an exception to the general prohibition on discrimination (Pritchard, 1995; Hunyor, 2009). The law does not go as far as to require such measures to be taken to achieve substantive equality; it only protects such special measures from challenge by people who are not eligible to receive their benefit.

Discrimination law may be a useful tool in combatting personally mediated racism: for example, stereotypes that result in a refusal or denial of service, or a lesser standard of care such as assumptions about levels of compliance for Aboriginal and Torres Strait Islander kidney patients. Discrimination law may also be used to challenge institutional racism when policies, procedures and practices treat Aboriginal and Torres Strait Islander people less favourably or result in disadvantage in practice. For example, consider patient communication failures that are the result of providing information in a standard, inaccessible format such as formal or technical English.

There are, however, a range of limitations to discrimination law as a tool for addressing racism (Harvey, 2012). The law is complicated and can be uncertain in its operation. Proving discrimination can be difficult and courts are reluctant to make inferences of discrimination in the absence of evidence (Hunyor, 2003; Gaze, 2015). A lack of clear, evidence-based criteria for decisions, such as non-compliance, may make it more likely for unconscious racial bias to operate and conscious bias easier to mask or deflect.

The legal system also relies on individuals to bring complaints and be prepared to take them to court or a tribunal if they cannot be resolved in conciliation. This can be intimidating, expensive and time-consuming. Individuals challenging large institutions for their experience of racism can pay a significant personal cost (Moreton-Robinson, 2007). In any event, most complaints settle

on confidential terms, which limits their potential for systemic change (Gaze, 2015).

The recently enacted *Human Rights Act 2019* (Qld) [HRAQ] offers a related framework for addressing systemic racism in the public health system, by including the right to access health services without discrimination. However, this falls short of a free-standing 'right to health' and the limitations in remedies available under the HRAQ (Schetzer, 2020) may make it a less useful tool for rights protection than existing racial discrimination laws.

Importantly, however, discrimination law is no barrier to pro-active measures that aim to address systemic barriers and improve outcomes for Aboriginal and Torres Strait Islander people. Such 'positive discrimination' is protected under the special measures provisions that recognise the limitations of formal equality approaches and the need for different treatment to achieve equity-

**Healthcare
action
framework**

We offer a conceptual framework which brings together these four domains to guide institutions and health professionals in their work to deliver better health care outcomes for Aboriginal and Torres Strait Islander people, including those with chronic kidney disease (Figure 1).

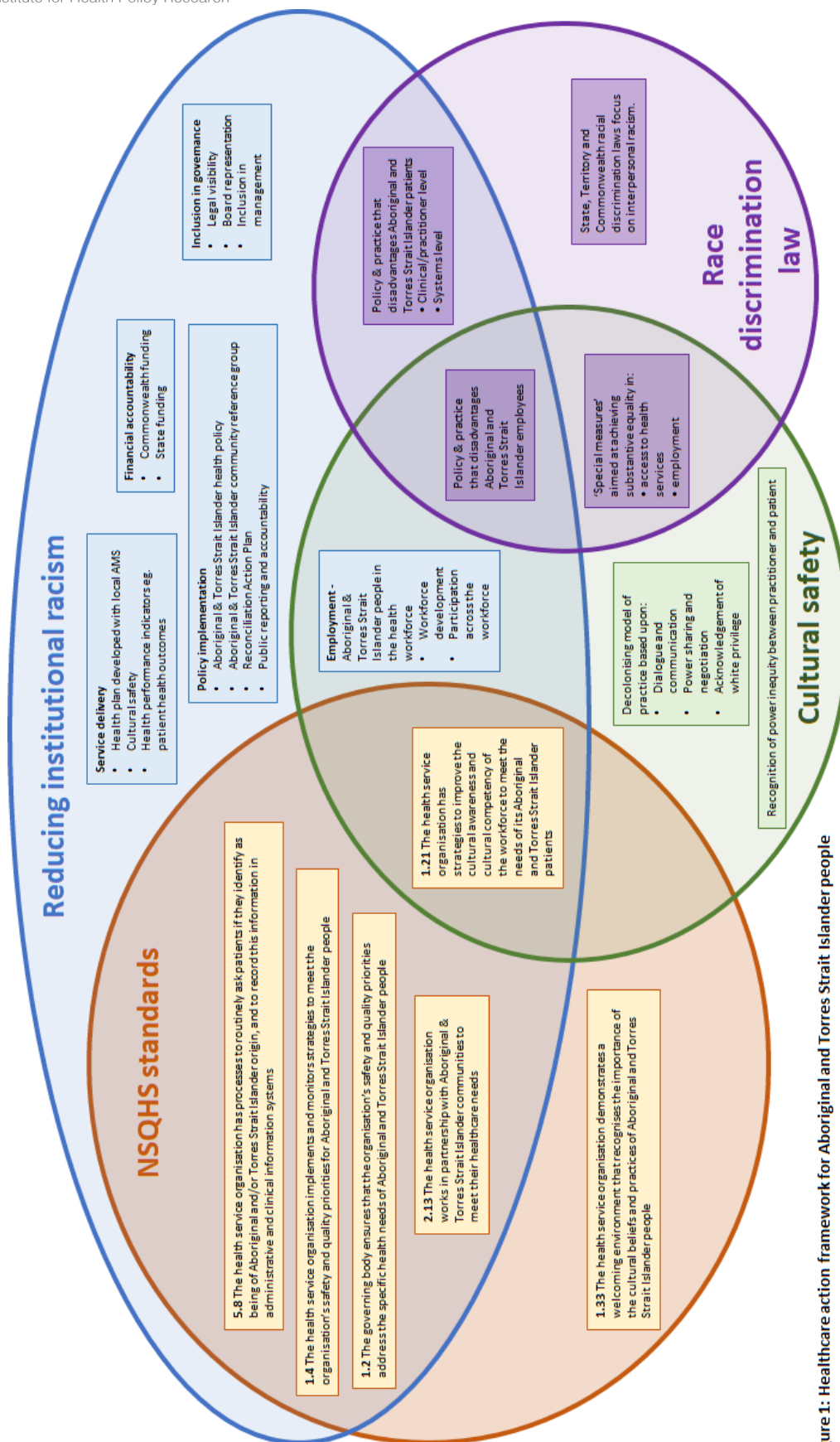


Figure 1: Healthcare action framework for Aboriginal and Torres Strait Islander people

Changes in kidney care

The changes required to achieve better kidney care outcomes for Aboriginal and Torres Strait Islander people are complex, dependent on multiple contextual factors that are not necessarily immediately visible, with the potential for overwhelming internal resistance. The majority of research on change in healthcare has focussed on the individual and interpersonal level for example, training of health professionals and understanding patient perspectives (Griffith et al., 2007).

Aboriginal and Torres Strait Islander healthcare research is no different. For example, a study that implemented a cultural respect framework in general practices in Sydney and Melbourne found no increase in Aboriginal health checks nor improvement in cultural respect scores (Liaw et al., 2019). However, tools to measure the ability of clinicians to provide cultural safety for Aboriginal and Torres Strait Islander patients are being developed and will require validation and adaptation for specific jurisdictional and geographic locations (Elvidge et al., 2019).

Changing organisations and systems requires different strategies. For example, the National Health and Medical Research Council (NHMRC) project “Return to Country: A national platform study to return Indigenous renal patients home” aims to identify and address health service level biases in order to increase the number of Indigenous patients able to return home for treatment with dialysis or a kidney transplant (Menzies School of Health Research, 2020).

Firstly, it will examine the relationship between Aboriginal and Torres Strait Islander patient health data, and renal unit- and hospital-level policies and procedures; secondly, it will test the critical reflexivity and courage of units and clinicians to embrace the changes needed to improve Aboriginal and Torres Strait Islander patient experiences and outcomes. Work is also underway to examine the effect of recent changes both to Medicare that provides funding for haemodialysis in remote settings, and to national criteria for deceased donor kidney transplant waitlisting (Menzies School of Health Research, 2020a).

Hospitals and healthcare organisations also need to change to reduce institutional racism, particularly as it affects policy and practice which are key drivers of the inequity in kidney care outcomes for Aboriginal and Torres Strait Islander people (Khanal et al., 2018).

A study of institutional racism in an Australian hospital demonstrated an emerging tide for change and the need for deeper inquiry to understand how senior leadership teams are effecting institutional transformation (Bourke et al., 2018).

Racial discrimination laws have a role in reducing institutional racism evident in policies and practices that discriminate against Aboriginal and Torres Strait Islander people. Given the limitations of the individual, complaint-based system, change is most likely to be seen if the need to avoid discrimination is factored into governance and risk-management by healthcare organisations.

There may be value in a broader human rights approach; asking, for example, 'how can we ensure Aboriginal and Torres Strait Islander people's right to health is protected'? A human rights approach is aligned with the long-standing Close the Gap Campaign for Indigenous Health Equality (Calma, 2016). This positive and forward-looking paradigm could drive systemic change. However, the need to make human rights relevant 'at the coalface' has been identified as essential to effectiveness (West et al., 2017). The blunt stick of potential racial discrimination litigation has an important role to play in focusing attention and providing an accountability tool. It is critical that the reality of race-based disadvantage is confronted head-on.

The intersection between these domains of cultural safety, institutional racism, the National Safety and Quality Health Service Standards, the race discrimination law and the identification of any gaps is identified by us as an additional area where more research is needed.

Call to action

- Queensland has provided national leadership by taking steps to ameliorate institutional racism through the co-designed development of an external monitoring and assessment matrix for their hospital and health services and then seeking to legislate for Aboriginal and Torres Strait Islander health equity. South Australia, is co-designing a similar external monitoring and assessment matrix with Aboriginal people including patients, health professionals and leaders. Other States and Territories should be following these examples.

- Complaints driven processes, such as race discrimination law, require monitoring and reporting mechanisms that demonstrate their effectiveness for Aboriginal and Torres Strait Islander people.
- Healthcare institutions need to reassess their exposure to the risk of successful litigation under race discrimination law for the persistent poor healthcare outcomes of Aboriginal and Torres Strait Islander people.
- Health researchers should start identifying gaps within the framework we have presented that may allow inequitable healthcare outcomes for Aboriginal and Torres Strait Islander people to persist.

Conclusion

Action is being taken at multiple levels to reduce the poorer healthcare outcomes provided by non-Indigenous health professionals and healthcare organisations to Aboriginal and Torres Strait Islander peoples.

We have identified four key intersecting domains of cultural safety, reducing institutional racism, the NSQHSS and race discrimination law that can guide and support improvements to the provision of kidney care for Aboriginal and Torres Strait Islander patients by non-Indigenous health professionals and healthcare organisations.

Locating additional areas within healthcare that permit the continuation of poorer outcomes for Aboriginal and Torres Strait Islander peoples is essential. Future reform should be co-developed with key stakeholders, including Aboriginal and Torres Strait Islanders and be based on evidence from rigorous and culturally appropriate research studies.

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