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# Receiving essential health services on country: Indigenous Australians, native title and the United Nations Declaration<sup>☆</sup>

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## ABSTRACT

**Objectives:** The aim of the study was to investigate the public health challenge to provide chronic disease management to Indigenous Australians who wish to remain on traditional lands and not cede tenure for health services.

**Study design:** Within the context of the United Nations (UN) Declaration on the Rights of Indigenous Peoples (DRIP), this research is intended to reveal health aspects requiring holistic consideration and thus enhance the resilience of Australia's First Nations Peoples. **Methods:** Lead authorship was by an Australian Aboriginal author, using methods of an information and literature review. A case study of chronic kidney disease illustrates the challenges remaining with native title land tenure.

**Results:** Despite continuing land tenure challenges, Indigenous Australians have demonstrated resilience and resourcefulness to engage and secure improvements in health and other basic services.

**Conclusions:** The Australian Government needs to revisit its duty to respect, protect and fulfil its obligation to the country's First Nations people in a human rights-based approach towards improved, accessible and culturally appropriate health care for chronic diseases.

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## Introduction

Securing land tenure arrangements on Indigenous land through leases ... is seen as a necessary requirement.<sup>1</sup> (Government of Australia, p.78).

Of particular concern for remote area communities [are the] 'National Investment Principles in Remote Locations' ... that involve removing decision-making powers of traditional land-owners and residents.<sup>2</sup> (Aboriginal Medical Services Alliance of the Northern Territory, p.7).

<sup>☆</sup> 'Country' is the term used by Aboriginal and Torres Strait Islander Peoples to refer to the estate or land traditionally occupied by distinct cultural groups. Country is central to Indigenous identity as it informs identity, history and cultural practices [47].

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The United Nations (UN) Declaration on the Rights of Indigenous Peoples ('the Declaration') [UN DRIP] was declared in September 2007 and affirmed that Indigenous individuals are entitled, without discrimination, to all human rights recognised in international law.<sup>3</sup> It was adopted by 143 countries voting in favour, 11 abstaining and four voting against.<sup>4</sup> Australia voted against the Declaration, predominantly owing to Article 26, which provides Indigenous people with the right to own and control lands they traditionally used, and this was thus interpreted by the Australian Government as placing customary law over national law.<sup>5</sup> This position was revised, and the Declaration was signed in 2009 after a change of the federal government and an inquiry to gather Australian Indigenous views on the Declaration.<sup>4</sup>

One aspect of the Declaration for which meaning and content is still challenged in Australia for Indigenous Australians is regarding the right to public health services and care as a basic human right for all. Article 23 stated that 'Indigenous peoples have the right to be actively involved in developing and determining health ... and social programs affecting them and, as far as possible, to administer such programs through their own institutions'.<sup>3</sup> Health is a common human right that includes Aboriginal and Torres Strait Islander Peoples. Despite gradual improvements in health outcomes, this population differs significantly in health to the general Australian population, and chronic disease incidences, including kidney disease, contribute two-thirds of this health gap.<sup>6,7</sup> The social and environmental determinants of health and well-being inequalities between Indigenous and non-Indigenous Australians are particularly challenging in more remote and isolated communities.<sup>8–11</sup>

This research seeks to investigate the public health challenge to provide chronic disease management to Indigenous Australians who wish to remain on traditional lands and not cede tenure for health services. These patients may also wish to avoid exchanging their traditional land tenure for local health services. The findings are intended to reveal aspects needing consideration and holistic responses to enhance the resilience of Australia's First Nations Peoples. This research is led by an Aboriginal researcher who brings both her personal and professional experiences to the analysis and scope of this topic.

## Methods

The information for this article was gathered through a broad literature and information review that sought to inform observations made by the lead author, who is an Aboriginal woman with ongoing connection to her traditional country and culture. In this way, she brings a personal and embedded exposure to the health and other impacts of colonisation. This experience provides a perspective through which the researcher's experiences verify the choice and analysis of the documented evidence.<sup>12</sup>

The information sought to explore that this research question exists in the published academic literature, relevant legislation and policies and in 'grey' literature, such as reports from civil society and government departments.<sup>13</sup> The reliance on grey literature was considered appropriate to fully

explore this little documented topic.<sup>14</sup> A case study of chronic kidney disease (CKD) is used to illustrate the challenges remaining with native title land tenure.

Of note, this article uses several terms interchangeably to refer to the original people of Australia. This includes the terms Indigenous Australians, Australia's First Nations Peoples, Australian First Nations' Peoples and Aboriginal and Torres Strait Islander Peoples (with intentional capitalisation), all of which have a degree of acceptance within these populations.<sup>15</sup> Australians who have migrated to the country since British colonisation began in 1788 are referred to as non-Indigenous Australians.<sup>16</sup>

## Background

### *Resilience of Australia's First Nations people*

There are numerous language groups and nations of Aboriginal and Torres Strait Islander Peoples that have endured across Australia, with many people maintaining between both traditional ways and other lifestyles.<sup>17</sup> Many Australians identifying as Aboriginal or Torres Strait Islander Peoples are familiar with their 'country', a term that refers to traditional lands.<sup>18</sup> Country forms a central focus of Aboriginal and Torres Strait Islander Peoples' identity, which, in turn, links to health.<sup>18</sup> For example, being in country provides supportive factors, such as cultural and social association and inclusion, while removal from country can create trauma from psychological stress.<sup>18</sup> The historical and ongoing impacts of colonisation have wrought social and emotional upheaval through loss of traditional lands, language and cultural identity and government policies that forced family separation and caused segregation and exclusion.<sup>19</sup> The ongoing associated health impacts can result in a deteriorated life expectancy and high morbidity.<sup>19</sup>

In recent decades, some redressing has occurred. In 1967, Aboriginal Australians were included in Australian citizenship and entitled to Commonwealth laws and benefits.<sup>20</sup> In 1992, the Native Title Act 1993 (Commonwealth) was adopted, formally recognising the tenure of traditional lands under Aboriginal and Torres Strait Islander Peoples.<sup>21</sup> In 2008, the Prime Minister delivered an apology to Australia's First Peoples; specifically on health, he proposed a future, 'where we harness the determination of all Australians, Indigenous and non-Indigenous, to close the gap that lies between us in life expectancy'.<sup>22</sup>

### *Health issues and services for Australia's First Nations: an example of CKD*

Despite the government's intention in 2008, nearly half of the Indigenous population reported having a disability or long-term chronic disease in 2015.<sup>21</sup> Social and cultural determinants, including the historical and cultural impacts, plus current levels of disadvantage, can describe approximately one-third of this health gap.<sup>21</sup>

One dominant chronic disease that is disproportionately expressed in Indigenous Australians is CKD. Although there has been a 47% decline in mortality from CKD between 2006

and 2015, almost one in five Aboriginal and Torres Strait Islander Peoples older than 18 years had indicators of CKD in 2012–13.<sup>7,23</sup> The incidence of end-stage kidney disease, which requires regular dialysis or a kidney transplant for survival, is especially high in remote and very remote areas of Australia, with a rate up to 20 times those of comparable non-Indigenous Australians.<sup>24</sup>

Linked to long-term management of chronic diseases, including CKD, for Indigenous Australians, attending medical clinics and hospitals can bring apprehension and fear, resulting in hospitalisation, which is seen as a ‘last-resort’ treatment option.<sup>6</sup> For those living in communities with small populations, public health services can be limited by distance, thus impacting on early diagnosis and treatment.<sup>6,25</sup> The UN Special Rapporteur on the Rights of Indigenous Peoples reported in 2017, after her visit to Australia, inequalities in remote primary health services and the essential role of these services in the prevention of chronic diseases.<sup>21</sup> This included references to the UN DRIP that acknowledges healthcare needs for Indigenous peoples.<sup>3</sup>

This situation is acknowledged in the National Aboriginal and Torres Strait Islander Health Plan that recommends Indigenous ‘patient journeys’ for CKD and other diseases meet both clinical health care as well as cultural and social needs.<sup>6</sup> This can be achieved through ‘place-based models of care’ that recognise and address access and delivery of health services due to barriers from geographic, language, cultural and behavioural differences.<sup>6,25</sup> A successful model of place-based health service is demonstrated by Aboriginal Community Controlled Health Organisations (ACCHOs): primary and preventative healthcare services designed and operated by the local Aboriginal communities.<sup>26</sup>

## Results

The objective of this research was to investigate the public health challenge to provide chronic disease management to Indigenous Australians who wish to remain on traditional lands and not cede tenure for health services, within the context of the UN DRIP, and to increase resilience of Australia’s First Nations Peoples. Three results emerged from the literature and case study: two dilemmas and one initiative. These are detailed in the following subsections.

### *Staying in country or leaving for health care to town?*

Chronic disease management is the central focus of Aboriginal and Torres Strait Islander primary health care, with defined protocols for integrated testing, management of chronic diseases and government support for medication for residents in remote communities.<sup>27</sup> However, many Aboriginal and Torres Strait Islander remote communities do not have access to in-community facilities, and residents are required to relocate to larger towns or cities. In early 2015, there were 305 dialysis patients receiving treatment in Alice Springs; of which, approximately 260 had relocated from remote Central Australian communities to access treatment.<sup>28</sup>

Documented stories from renal patients emphasise a common wish to remain in country and receive dialysis

treatment at home. These stories include positive statements regarding country and community, such as ‘country heals you’ and that blood pressure is lower from being active while hunting, fishing and camping and that bush tucker (traditional food) is healthier than town food.<sup>29</sup> The negative aspects of moving to town during treatment are the loneliness from missing country and family, the high cost of transport and accommodation (and an associated risk of temporary homelessness or ‘camping in the long grass’), the difficulty in understanding medical systems and terminology and the fear of dying away from country.<sup>29</sup> At a community scale, the significant number of older community residents leaving for long stays during renal treatment results in the absence of their direct knowledge of cultural country and cultural traditions; this has been described as a ‘conjunction of cultural loss with the health crisis and its impacts on the social control, leadership, authority and familial support networks of communities’ (p.30).<sup>2</sup>

### *Relinquishing land tenure to gain in-community health facilities*

Australian Indigenous land rights, under the framework of the Native Title Act 1993 (Cth), exist under a range of legislative arrangements in most states and territories to provide for Indigenous ownership of land through various forms of tenure.<sup>1</sup> However, a dilemma has arisen for remote communities to relinquish their rights to the federal government for the provision of in-community services.

At a national level, the Council of Australian Governments’ agreement in 2009 outlined investment principle for remote locations. Although the opening statement noted that ‘remote Indigenous communities ... are entitled to standards of services and infrastructure broadly comparable with that in non-Indigenous communities of similar size, location and need’ (page A-23), the later principle encourages a relocation of individuals to larger centres with secure leases.<sup>2,30</sup>

In 2013, the National Partnership Agreement on Remote Service Delivery (NPARSD) conditioned communities to sign long-term leases with the governments. The NPARSD states that land tenure arrangements on Indigenous land through leases or other agreements are required before substantial government investments, such as housing and other infrastructure (paragraph 17(l)).<sup>1</sup> It requires place-specific local implementation plans for primary healthcare clinics, including renal infrastructure and dialysis and support services.<sup>1</sup> This conditional provision of community leases in return for health services, among other services and assets, has been noted by Indigenous organisations as a limitation to self-determination.<sup>2</sup> In doing so, the community cedes their control in local decision-making.

The Northern Territory (NT) is a federal territory (not a state), with limited self-government.<sup>31</sup> The Australian Government retains land tenure issue interests in the NT through its responsibilities under the Aboriginal Land Rights (Northern Territory) Act 1976 (Cth), amended in 2006, and the Stronger Futures in the Northern Territory Act 2012 (Cth).<sup>1</sup> Both of these acts can significantly affect local decision-making by Indigenous community residents over their decision-making and access to health services. The Stronger Futures in the

Northern Territory Act 2012 (Cth) allows modifications of laws applicable to town camps and community living areas to facilitate 'the granting of rights and interests, and promoting economic development, in those camps and areas' (Part 3).<sup>32</sup>

Under the Aboriginal Land Rights (Northern Territory) Amendment Bill 2006 (Cth), a land trust may grant a 99-year lease of a township to an approved entity with the Minister's or relevant Land Council's consent (provided that the community understands the nature and purpose of the lease and that the terms and conditions are 'reasonable').<sup>33</sup> The traditional owners of the land who choose to grant a 99-year lease will cede the ability to determine how their land is used, and the head lease would be held by a Commonwealth officer.<sup>33,34</sup>

A large number of opposing submissions were received by the inquiry into the Aboriginal Land Rights (Northern Territory) Amendment Bill 2006 (Cth). This includes criticism that the amendments undermined native title rights through the 99-year leases removing traditional owners' control over decision-making in relation to their community land.<sup>35</sup> One Aboriginal organisation stated that the Northern Territory Aboriginal Land Rights Act 1976 already allows for leasing for a variety of purposes and to any party.<sup>36</sup> The 99-year leases enabled through the amendments allow subleasing to other parties, but without traditional owner's consent or decision, thus could also prevent traditional owners from participating in possible commercial opportunities arising.<sup>37</sup>

An example of the Aboriginal Land Rights (Northern Territory) Amendment Bill 2006 (Cth) under implementation occurred on the day the Bill was debated in the Federal House of Representatives. The remote NT community of Galiwin'ku was offered 50 houses and associated construction jobs and police, education and health services by the Federal Minister for Indigenous Affairs at the time. To receive this assistance, the traditional owners of Galiwin'ku were required to sign a lease of their township land for 99 years.<sup>37</sup>

### **Resourcefulness to overcome the healthcare barriers**

In the 1990s, remote Western Desert 'tristate' Pintupi and Luritja communities of Kiwirrkura (Western Australia), Mount Liebig (NT) and Kintore (Walungurru; NT) saw many residents forced to move to Alice Springs for renal dialysis. Patients suffered loneliness and dislocation away from country and family, and the remaining community members felt the loss of knowledge and leadership.<sup>38</sup> Until 2001, no community-based care was offered or funded.<sup>39</sup> In a creative response that reflects the communities' resilience, Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT; an ACCHO, translated as 'making all our families well') reviewed the dilemma from the perspectives of community residents, health professionals and funding organisations to find a culturally appropriate and community-appropriate option.<sup>39</sup> To financially support local residents to independently remain on country for medical treatment, more than one million dollars was raised for the WDNWPT by artists from Kintore and Kiwirrkura. They created artworks that were auctioned with additional donated artwork at the Art Gallery of NSW in 2000 as the 'Western Desert Dialysis Appeal'.<sup>40</sup>

By 2005, the NT Department of Health had established a partnership with the WDNWPT to support the 'Going Home

program', a reverse-respite initiative where only short periods were spent in Alice Springs for peritoneal and haemodialysis, followed by a 3-week stay in the home community with clinical assistance from the primary healthcare clinic.<sup>41</sup> In addition, self-care dialysis was established with local government assistance in the NT's Jawoyn, Tiwi Islands and East Arnhem.<sup>41</sup>

The in-community dialysis services are now also known as Western Desert Dialysis and the Purple House.<sup>42</sup> A 2014 independent evaluation estimated, with adjustments, that the cost per treatment of patients in the WDNWPT model was one percent less expensive than the National Efficient Price used to determine funding for hospital-based dialysis treatment.<sup>40</sup> Perhaps, more revealing was the conclusion that the model provides 'a range of financial and non-financial benefits to government and other stakeholders' that were not included in cost calculations.<sup>40</sup>

The UN Special Rapporteur on the Rights of Indigenous Peoples emphasised this when visiting Australia in her comment on how the 'need for cultural connection is essential to achieve sustainable improvement in health indicators'.<sup>21</sup> However, as described in the Results section, CKD sufferers are faced with a requirement to relinquish land tenure to the government to secure in-community health services and other services and infrastructure. In this example, some Indigenous communities have sought to ensure their self-determination by finding an alternative way to fund in-community dialysis through their community members' strengths in creating artwork. Yet self-funding essential health care and services does force a consideration of Article 23 of the Declaration regarding the right of Indigenous peoples to develop and determine appropriate health programs when funding is not assured by the state.<sup>3</sup>

Despite these continuing challenges, Indigenous Australians have demonstrated resilience and resourcefulness to engage and secure improvements in health and other basic services. This should occur in collaboration with a supportive state, where their needs are centrally considered. This aligns with the 'Redfern Statement' of 2016. Regarding health, it states as follows:

*The health and wellbeing of Aboriginal and Torres Strait Islander Peoples cannot be considered at the margins. It is time that Aboriginal and Torres Strait Islander voices are heard and respected.*<sup>43</sup>

### **Discussion: the role for a rights-based approach to deliver remote health services**

The Results section describes the dilemma for CKD and other patients with chronic diseases between staying in remote country and leaving for health care to towns. If residents advocate for in-community health facilities from government, this can raise the challenging requirement to relinquish land tenure in return for long-term services. This has motivated some resourceful communities to seek independent finance for such services.

This situation reveals a disconnect with the Australian government's responsibility for 'closing the gap' by increasing access to quality health services to reduce the disadvantages experienced by Aboriginal and Torres Strait Islander Peoples. Given the cultural diversity of Australian Indigenous Peoples, the government—as the duty bearer—needs to demonstrate accountability by negotiating with the traditional owners who hold the right to decisions on the development and improvement for kidney dialysis in remote Aboriginal communities, especially around state borders. States are obliged to fulfil a human rights-based approach.<sup>44</sup> A human rights-based approach goes beyond human development approaches by recognising that to achieve human development outcomes, human rights must be realised by those whose development is at stake.<sup>45</sup> For the delivery of services to Aboriginal peoples especially in remote areas, a rights-based approach calls for existing resources to be shared more equally and for assisting the marginalised people to assert their rights to resources, including health services.<sup>44</sup> This can be implemented, for example, by allowing Indigenous people to access better health in the area where their language is spoken, to better understand how they need to address their health issues with kidney disease.

Under international law, the state is the principal duty-bearer with respect to the human rights of the people living within its jurisdiction.<sup>44</sup> In reflecting on the legislation, it requires land tenure to be ceded for essential health services and housing infrastructure, for example, the federal and NT governments should have respect towards Aboriginal people in remote areas and take in the specific needs that are necessary to better health. Actions based on a human rights-based approach are based on legal and moral obligations to carry out a duty that will permit a subject to enjoy her or his rights.<sup>45</sup> All Indigenous Australians have the fundamental human right to their traditional land and their connection to their land, which is of central importance to their identity and culture. They should not be required to cede decision-making control through 99-year leases with governments in Australia: a country where health is funded and provided by all levels of local, state, territory and federal government.<sup>46</sup>

## Conclusions

Australians encounter the public health system at birth and engage with it frequently during key moments of health and ill health throughout their lives. However, for Aboriginal and Torres Strait Islander peoples—especially those living in remote areas—their 'patient journey' through the public health system can be insufficient, discriminative and unequal to their needs.

This research reflected on the eight years since Australia signed the UN Declaration on the Rights of Indigenous Peoples, with a specific consideration of access to health services for Australian Aboriginal and Torres Strait Islander peoples who require chronic disease treatment yet are located in remote communities. Australia's delay in signed the Declaration—owing to queries regarding native title of lands—remains a key theme through this research. As described, Indigenous residents of remote communities do not wish to

leave their traditional country for treatment of chronic diseases, such as kidney dialysis.

In continuing to formally recognise the rights of Australian Indigenous peoples and to uphold the Declaration, the Australian Government needs to revisit its duty to respect, protect and fulfil its obligation to the country's First Nations people in a human rights-based approach towards improved, accessible and culturally appropriate health care for chronic diseases.

## Author statements

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### Competing interests

None declared.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2019.08.024>.