Investigating equity in access to Australian clinical genetic health services for Aboriginal and Torres Strait Islander people

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Abstract

Globally, there is a recognised need for a greater commitment to an equity agenda in clinical genomics and precision medicine. Fundamental to this, is the equitable access by all to services providing genomic health care. However, achieving this remains constrained by a paucity of evidence that quantifies (in)equity of access to clinical genomics, particularly amongst Indigenous populations. Using administrative data from clinical genetic health services located in three jurisdictions (States/Territories) in Australia, we investigate equity in the scheduling and attendance of appointments among Aboriginal and/or Torres Strait Islander people, compared to non-Aboriginal and/or Torres Strait Islander people. For 15554 appointments scheduled between 2014-2018, adjusted Multivariate Poisson Regression models revealed that Aboriginal and/or Torres Strait Islander people were scheduled fewer appointments (IRR 0.73 [0.68-0.80], <0.001) and attended at lower rates (IRR 0.85 [0.78-0.93], <0.001). Within this population, adults, females, people living in remote locations, and those presenting in relation to cancer or prenatal indications experienced the greatest disparity in access. As the first quantitative, multi-jurisdictional study to measure access to clinical genetic health services, these results provide important baseline data related to the reach and equity of these services in Australia and contribute to the global effort to address equity in genomic health.

Background

Globally there is a robust and growing evidence base that reveals inequitable access and outcomes across health systems for Indigenous populations. For Aboriginal and/or Torres Strait Islander populations, research reveals disparities in access to the Australian health system and the clinical services it provides, including diagnostic investigations, procedures, care planning, treatments, as well as service adherence to best practice treatment guidelines [1-11]. However, to date, access to clinical genetic health services has not been quantified among Aboriginal and Torres Strait Islander populations. Here we focus on public clinical genetic health services that sit within the broader Australian health system, which is known to produce racialised health inequities[12]. This research recognises that similar health system inequities, leading to disparities in health outcomes, are experienced by Indigenous populations globally [13].

Genomic medicine is now recognised as a standard component of health care [14]. Clinical genetic health services are key providers of genomic medicine, a rapidly evolving field that has demonstrated benefits for individuals and families across the life-course [15]. Working with molecular and cytogenic laboratories, clinical genetic health services provide diagnostic assessments and molecular confirmation of disease or disease risk, supported by genetic counselling. In Australia, individuals and families are referred to clinical genetic health services by general practitioners (GPs) (i.e. primary care providers), hospitals and specialists, as well as through self-referral pathways in some jurisdictions. For people with or at risk of genetic conditions, including hereditary cancer syndromes and rare diseases, clinical genetic health services provide substantial health benefits through diagnosis, prevention, medical advice, education, and counselling [16].

Despite the current paucity of any data globally that relates to access to clinical genetic health services and the concomitant benefits they provide, there is a recognised need to improve equity in access to clinical genetic health services and inclusion in genomic research among Indigenous populations [17,18]. To fulfil this objective, there is a critical need for clinical genetic health services and researchers to work with individuals, families and communities to understand where disparities lie, why they arise, and how to work in partnership to design more equitable services [14]. In Australia, promoting equity in genomic health requires a shift from service design *for* to *with* Aboriginal and Torres Strait Islander peoples. It also requires recognition of the historic and ongoing racism experienced by Aboriginal and Torres Strait Islander peoples in Australian health settings more broadly, including acknowledgement of how research and clinical practices have made inappropriate and unethical use of Aboriginal and Torres Strait Islander peoples' genetic information in the past, as well cognisance that Australian medical research practices and health service delivery models were developed by and for the dominant culture, with minimal consideration of cultural safety and responsiveness to the needs of Aboriginal and Torres Strait Islander communities. These few brief points provide some context as to why both engagement with and access to clinical genetic health services may be different for Aboriginal and/or Torres Strait Islander populations [19,20].

Against this backdrop, qualitative studies have shown that Aboriginal and Torres Strait Islander people wish to be included in the benefits offered by genomic medicine by having access to clinical genetic health services. Wild *et al.* (2013) found that there was clear demand among Aboriginal women for genetic investigations and counselling in the antenatal period and Bernardes *et al.* (2014) similarly showed that many Aboriginal and Torres Strait Islander people with cancer were interested in discussing with a genetic specialist the subsequent risk of cancer among family members [21,22]. Australian health policy has further recognised the importance of identifying and addressing barriers to genetic health services for Aboriginal and Torres Strait Islander people. The National Health Genomics Policy Framework and Implementation Plan 2018-2021, states as part of its mission that the integration of genomics into the health system must proceed in '*an efficient, effective, ethical and equitable way*' [23]. The Framework specifically targets Aboriginal and Torres Strait Islander peoples in three priority areas for action: evaluating the accessibility, appropriateness and cultural responsiveness of clinical genetic health services, increasing genomic literacy of health providers working with Indigenous populations and ensuring culturally safe data collection in order to reflect diversity [23].

Responding to these factors, the aim of this research is to investigate equity in access to clinical genetic health services by examining rates of appointment scheduling and attendance among Aboriginal and/or Torres Strait Islander people in three Australian jurisdictions: the Northern Territory, Queensland and Western Australia. This research makes an essential contribution to the field of health equity research as it is the first study globally that quantitatively reports access to clinical genetic health services in an Indigenous population.

Results

In total, 17,801 people had an appointment scheduled across the three clinical genetic health services for the years examined. Of these, 15554 people had Aboriginal and/or Torres Strait Islander status recorded and are included in these analyses.

Of the total 4,285 appointments scheduled annually, 3.4% were scheduled at the Northern Territory Genetics Service, 56.2% at Genetic Services of Western Australia, and 40.4% at Genetic Health Queensland. Reflective of the population distribution in the three jurisdictions, Aboriginal and/or Torres Strait Islander people comprised only 20.4%, 3.3% and 4.2% of all scheduled appointments in the Northern Territory, Western Australia and Queensland respectively.

In total, 4.4% of all scheduled appointments were for people who identified as Aboriginal and/or Torres Strait Islander people. The subsequent analyses describe equity in appointment scheduling and attendance for these people.

Appointment scheduling

Characteristics of people for whom an appointment was scheduled

Aboriginal and/or Torres Strait Islander people who were scheduled an appointment were younger, less likely to reside in major cities and less likely to be referred by a specialist in comparison to non-Aboriginal and/or Torres Strait Islander people (Table 1). Gender ratios differed for Aboriginal and/or Torres Strait Islander people relative to non-Aboriginal and/or Torres Strait Islander people. Aboriginal and/or Torres Strait Islander people were more likely to have a telehealth appointment overall. However, excluding people from major cities, Aboriginal and/or Torres Strait Islander people from regional and remote areas were less likely to have a telehealth appointment (9% vs 14%).

In terms of reasons for the appointment, a greater proportion of Aboriginal and/or Torres Strait Islander people were scheduled an appointment for a rare disease than for cancer and prenatal reasons in comparison to non-Aboriginal and/or Torres Strait Islander people. For Aboriginal and/or Torres Strait Islander people, the rate of scheduling appointments for prenatal reasons was 72% lower, with only two appointments scheduled annually for Aboriginal and/or Torres Strait Islander people across the three states.

Characteristics of Aboriginal and/or Torres Strait Islander people who were scheduled an appointment at a clinical genetic health service differed by state and are described in Table 2. In the Northern Territory, most people were under 20 years of age (77.7%) and most were scheduled an appointment for a rare disease. Conversely, in Queensland, more Aboriginal and/or Torres Strait Islander people were scheduled an appointment at an older age, although half (49.1%) were still aged under 20 years. In Queensland one in three appointments scheduled was for cancer, compared to one in ten appointments in the Northern Territory and one in five in Western Australia. In Queensland, unlike the Northern Territory and Western Australia, there was an observed gender differential among Aboriginal and/or Torres Strait Islander people, where females were more likely to be scheduled an appointment than males.

Darwin and Alice Springs (the two largest cities in the Northern Territory) are classified under the ASGS remoteness structure as outer regional and remote, respectively. As a result, no individuals in the Northern Territory lived in major cities. People in the Northern Territory were more likely to live in regional (54.5%) and

remote (45.5%) areas, while in Western Australia and Queensland, half of appointments scheduled were for people living in major cities (i.e. Perth and Brisbane). In Western Australia 26.3% of scheduled appointments were for people residing in remote areas, while for Queensland this figure was 4.9%.

A vast majority of referrals in the Northern Territory came from a specialist (94.6%), whereas in fewer referrals came from a specialist in Western Australia (62.5%) and Queensland (63.45%), with the rest from a general practitioner, other clinician or by self-referral.

Equity in appointment scheduling

Based on univariate modelling, incidence of appointment scheduling was 46 per 100,000 Aboriginal and/or Torres Strait Islander people annually compared to 57 per 100,000 for non-Aboriginal and/or Torres Strait Islander people. This reflects an under-scheduling rate of 19.2% (Table 3). If there were parity in appointment scheduling, we would have expected to see 42 additional appointments scheduled annually for Aboriginal and/or Torres Strait Islander people across the three states. Under-scheduling for Aboriginal and/or Torres Strait Islander people was greatest amongst adults, people residing in remote areas, and females. The greatest disparity was observed in the Northern Territory, where incidence scheduling was 40 per 100,000 for Aboriginal and/or Torres Strait Islander people compared to 67 per 100,000 for non-Aboriginal and/or Torres Strait Islander people.

There did not appear to be disparity in appointment scheduling for rare diseases (excluding prenatal appointments as a subcategory of rare disease). However, for cancer and prenatal reasons, scheduled appointments were 55.8% and 71.4% lower for Aboriginal and/or Torres Strait Islander people.

Attendance at appointments

Characteristics of people attending an appointment

Annually, 75.4% of Aboriginal and/or Torres Strait Islander people attended a scheduled appointment compared to 86.5% of non-Aboriginal and/or Torres Strait Islander people (Table 4).

For Aboriginal and/or Torres Strait Islander people, attendance was lowest for people in the 20-29 year age group, and males. Unlike non-Aboriginal and/or Torres Strait Islander people, where attendance decreased with remoteness, attendance for Aboriginal and/or Torres Strait Islander people residing in a major-city (71.1%) and remotely (72.9%) were similar. The reason for the appointment did not impact attendance. All prenatal appointments were attended. However, caution must be used in interpretation of this finding as there were only two prenatal appointments annually for Aboriginal and/or Torres Strait Islander people.

Attendance overall was lowest in Western Australia, with 65.0% of Aboriginal and/or Torres Strait Islander people attending (compared to 76.7% in the Northern Territory and 86.1% in Queensland) and 79.6% of non-Aboriginal and/or Torres Strait Islander people attending (compared to 94.3% in the Northern Territory and 95.6 % in Queensland). Rate ratios for each jurisdiction reveal that despite differences in attendance by state, rate ratio odds were consistently 18% lower for Aboriginal and/or Torres Strait Islander people compared to non-Aboriginal and/or Torres Strait Islander people.

Equity in Appointment scheduling and attendance-multivariate analysis

In multivariate analysis adjusting for age, gender and state, IRR revealed that Aboriginal and/or Torres Strait Islander people were 27% less likely to be scheduled an appointment at a clinical genetic health service and attended appointments at a 15% lower rate than non-Aboriginal and/or Torres Strait Islander people ($p < 0.001$, Table 5).

Discussion

This paper is the first to quantify access to and use of clinical genetic health services for an Indigenous population across multiple jurisdictions within a country. Our analyses provide clear evidence for marked inequity in access for Aboriginal and/or Torres Strait people, both in terms of appointment scheduling and attendance at clinical genetic health services across three jurisdictions. These findings are of importance to clinical genetic health services within Australia, as well as to health services globally as they consider and advance the equitable provision of genomic and precision medicine.

To contextualise these findings, we draw on the literature relating to genetic health service inequities for marginalised populations in Australia, New Zealand, Canada and the US. This literature has largely taken an ecological perspective and a qualitative approach to describe many factors contributing to inequity at the individual, interpersonal, health system levels (Figure 1).

At the individual level, this literature speaks of individual awareness, knowledge, attitudes, values, preferences and priorities [24-28]. At the interpersonal level–that is, the patient-practitioner interface–the literature identifies the possible contribution of referring practitioners and genetic health practitioners to inequity [21,29-31]. At the health system and society level the literature highlights the Eurocentric biomedical health model with its emphasis on individualism and autonomy, the pro-white bias (or whiteness) of delivery and standardisation of care, as well as geographical proximity to services [14,26]. These inequities are also exacerbated by the high non-medical costs associated with attending services, particularly for patients in rural and remote settings travelling long distances to access services. Addressing inequities in access to clinical genetic health services is likely to involve intervention across each of these levels.

As we consider inequities in access to Australian clinical genetic health services, we draw on these ecological understandings and consider further spatial and temporal dimensions including that of past and ongoing colonialism. We consider the role that medical professionals, researchers and policy makers have played in Australia and globally in the construction of dehumanising, racialised knowledge that claimed to show that Indigenous minds, bodies and cultures were inferior or less fit [32]. In particular, it was Australian state governments that drew on racial science, including the pseudoscience of eugenics, in their attempt to eradicate and 'breed out' Aboriginal and Torres Strait Islander people, including through official assimilation and segregation policies [33,34]. All these factors at the individual, interpersonal, and health system level within the context of ongoing colonisation, provide insight to the inequities experienced by Aboriginal and/or Torres Strait Islander people that we report here.

We found significant under-scheduling of appointments for Aboriginal and/or Torres Strait Islander people, with disparities most marked for those from remote areas, adults, and those referred for cancer or during the prenatal period. Under-scheduling of appointments in remote areas is likely reflective of a referral bias, where opportunity

for referral is restricted by the limited availability of both general practitioners and specialist services in remote areas [35]. It may also reflect a relative lack of awareness of genetic and rare diseases in primary care when compared to specialist care. This speaks to a need for increased awareness in primary care, enhanced referral pathways in the absence of general practice and specialist services (including self-referral to clinical genetic health services). Additionally, the relative lack of telehealth appointments may reflect a requirement to increase and tailor provision of telehealth services to meet the needs of Aboriginal and Torres Strait Islander people. This has become acutely apparent in the provision of other health services during the COVID-19 pandemic [36]. There may also be specific considerations for improving telehealth for genetic health care that cater to the frequently familial nature of diseases and consultations, and support confidentiality and culturally appropriate mechanisms of gaining informed consent.

Across jurisdictions there was under-scheduling of appointments for adults, which could be explained by low rates of prenatal and cancer appointments. Given that both Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander populations are heterogenous and that there is no prima facie reason to expect lower susceptibility to either rare genetic conditions in pregnancy or hereditary cancer in Aboriginal and Torres Strait Islander people, it is unlikely that this discrepancy in access reflects a biological driver. Indeed Allford *et al.* (2014), drawing on a study by Hall *et al.* (2009), highlight that mutations in the Mendelian genes that confer hereditary susceptibility to cancers occur in equal frequency across different ethnic groups [37]. Further, as the Australian Institute of Health and Welfare reported in 2018 using national morbidity data, Aboriginal and Torres Strait Islander populations were 10% more likely to be diagnosed with cancer in 2009-2013, which we would have expected to precipitate a higher, not lower, rate of appointments scheduled for Aboriginal and Torres Strait Islander people [38]. Also, consistent with our findings, a review of studies from the United Kingdom, North America and Australasia revealed lower rates of access to services for cancer among minority social groups [37]. We recognise that cancer discourse relating to Aboriginal and/or Torres Strait Islander people is consistently framed as a consequence of individual deficits in behaviours and lifestyle choices (such as smoking), and this stigmatisation may also contribute to under-referral [39].

In terms of prenatal appointment scheduling, only one appointment was scheduled for Aboriginal and/or Torres Strait Islander people across the three states per year; a rate 72% lower than non-Aboriginal and/or Torres Strait Islander people. However, based on higher fertility rates, it would be expected to see more appointments scheduled for Aboriginal and/or Torres Strait Islander women who, across their lifetime, have an average of 2.32 babies per woman compared to 1.66 babies per non-Aboriginal and or/Torres Strait Islander woman [40]. Arabena (2006) highlights the importance of sexual and reproductive rights as a means to improve the lives of Aboriginal and/or Torres Strait Islander people [41]. These sexual and reproductive rights include access to services and information, including prenatal screening and testing as well as reproductive genetic counselling for people at risk pre-conception. It must also be considered that Aboriginal and/or Torres Strait Islander women's experiences of medical care continue to be impacted by historical policies of forced child removal and sterilisation [42].

It is encouraging that our data reveals that Aboriginal and/or Torres Strait Islander children in the 0-9 and 10-19 year age groups are being scheduled appointments with equal frequency to non-Aboriginal and/or Torres Strait

Islander children. One underlying factor for the greater likelihood of rare diseases being referred during childhood, when there is more frequent contact with the health system, thereby providing more opportunity to receive a referral. Also based on the Northern Territory experience, there has been an ongoing policy and practice focus on paediatric care initiatives, including outreach by paediatric teams. Exploring such factors that have supported the apparent relative equity in referrals for paediatric clinical genetic care provision will provide insights for adult service provision.

In terms of equity, we reported attendance lowest for Aboriginal and Torres Strait Islander people in the 20-29 year age group, people identified as male and for appointments made in relation to cancer. These groups would likely benefit from further support to attend appointments. As non-attendance includes an appointment being cancelled, moved, or not attended we were unable to ascertain if attendance reflects individual or service-level factors. For age, the lower attendance for those aged 20-29 may reflect competing social responsibilities (caring for children, work, family responsibilities) impacting this age group, which may require rescheduling and cancelling of appointments. Younger adults may not be as familiar with or engaged in navigating health services, which could also impact attendance. With regard to gender, there was lower attendance for people identified as male in both populations, which is consistent with the findings of other research [43]. In interpreting this finding, we draw on the work of Canuto *et al.* (2018) who found a high level of motivation amongst adult Aboriginal and/or Torres Strait Islander males to attend preventative health care, but that logistical factors, lack of promotion of services, inadequate communication, and lack of culturally appropriate and gender-specific services were barriers to health service utilisation [44]. Our finding of lower rates of attendance at clinical genetic health services for cancer-related appointments may reflect variations in care coordination between disease domains and age groups. We did not find there to be differences in attendance among Aboriginal and/or Torres Strait Islander people based on remoteness, suggesting that the overall attendance disparity observed between remote and non-remote patients relates to differences in rates of referral.

We also found variation in scheduling and attendance at the jurisdictional level. For example, In Queensland, there were significantly more referrals that came from GPs as a proportion of all referrals, which may contribute to the higher referral rates for adults in comparison with other jurisdictions. In Queensland, we also found an observed gender differential where all females were more likely to be scheduled an appointment than males. Given the greater rate of referrals for prenatal reasons and cancer in Queensland, this gender differential may be indicative of higher referral during pregnancy as well as for cancers, many of which are for females ascertained by a family history of breast cancer. Yet for all states, despite their geographical differences and different service models, attendance was consistently 18% lower among Aboriginal and/or Torres Strait Islander people. Understanding the factors outside of those measurable here that underlie the differences between jurisdictions will provide insights for improvements.

The strengths of this cross-sectional study include the relatively large number of people in the study and its inclusion of several jurisdictions within a single country. The numbers provide statistical power, the multi-

jurisdictional nature allows for comparisons between service models and the national nature provides some bounds from within which to consider the variability.

Limitations of our analyses are that the data we draw from are administrative appointment databases that have common features, but also differences in data structure, which limits the number and type of factors that can be assessed. Inequities in access can occur at multiple points in a patient journey, including before, during and after an episode of clinical service. The design of this study provides the greatest insights at intermediate and later stages of the patient journey. Further research would be useful to provide insight into drivers of lower referral rates among Aboriginal and Torres Strait Islander people.

We also recognise that Aboriginal and Torres Strait Islander status was missing for one in five people from one jurisdiction (WA). This provides a significant opportunity for improved data collection to enable targeted provision of culturally responsive care and has been acknowledged as a key objective at both the service- and system-level in this jurisdiction as a result of our findings.

The cross-sectional nature of this analysis means that although we can demonstrate inequity in appointment scheduling and attendance, we cannot definitively determine causation, nor what is driving inequity. Nor can we make definitive conclusions on the quality of the individual episodes of care.

In concluding, the analyses presented herein quantitively identify key areas for consideration for improved equity of access to clinical genetic health services by Aboriginal and/or Torres Strait Islander people across three Australian states. These findings are likely to provide insights for other Australian jurisdictions and other countries.

Our findings of inequity highlight the need to consider alternative pathways and models of care to improve equity for Aboriginal and/or Torres Strait Islander people. Elsum *et al*. (2020) describe a model of genetic care which has achieved improved access to genomic medicine for Aboriginal people in remote parts of the Northern Territory. This model highlights the benefits of a implementing a community-based, person- and family-centred approach [45]. The family-centred approach to clinical genetic health service provision has also been identified as an important enabler among Māori, the Indigenous people of Aotearoa (New Zealand) [14].

The global literature also highlights various points at the individual, interpersonal and system levels at which inequity in clinical genetic health service access may be addressed. A study by Reilly *et al.* (2018) that examined access to clinical cancer services by Aboriginal people found that access improved using a multilevel approach to co-ordinated care. This approach had an emphasis on navigating the health system, providing appropriate information and communication, assisting with the management of multiple and competing social stressors in the home, and was underpinned by cultural safety [46]. These learnings are likely transferable to the clinical genetic health setting. Further, Elsum *et al.* (2020) in talking to clinical genetic health services highlight the important need for co-design approaches to ensure our health services are both accessible and culturally safe [45].

The analysis revealed there were groups who were shown to be under-represented in appointment scheduling and attendance who would benefit from strategic investment, including adults requiring services during the prenatal

period, adults and their family members diagnosed or at risk of cancer, people in remote areas, and people attending primary care irrespective of geographical location.

Data presented here reveal marked inequities in access to clinical genetic health services for Aboriginal and/or Torres Strait Islander people in terms of lower rates of appointment scheduling and attendance and should be used to inform interventions to improve equity to clinical genetic health services.

Online Methods

Ethics and approvals

We have complied with all relevant ethical regulations. Ethics approval was obtained from the following Human Research Ethics Committees: The University of Melbourne (HREC-1648489.4), Northern Territory Department of Health and Menzies School of Health Research (HREC-2018-3075) and the Central Australian Health Service (HREC-18 3112), The Queensland Department of Health (HREC/18/QTHS/51), the Aboriginal Health Council of Western Australia (HREC-810) and the King Edward Memorial Hospital (RGS0000000513). The Aboriginal Medical Services Alliance Northern Territory, Machado-Joseph Disease Foundation, Bega Garnbirringu Health Service (Kalgoorlie), and the Aboriginal Health Council of Western Australia (via Ethics support), all provided formal support for the project. Additional support for the project was received from 14 Aboriginal Health Organisations that were involved in extensive stakeholder consultation and engagement activities.

Study setting

In Australia, there are eight states and territories, each with its own model of clinical genetic health service provision. We draw on data from three of these: Queensland, Western Australia, and the Northern Territory. Queensland and Western Australia operate a 'hub and spoke' service model, with regular outpatient clinics undertaken in the capital cities of Brisbane and Perth, respectively, and semi-regular outreach clinics held in inner- and outer-regional areas. The Northern Territory operates a fly-in, fly-out service, comprising approximately four blocks of four consulting days per year in the two largest cities, Darwin and Alice Springs. Combined, the three jurisdictions have a resident population of 7.65 million people, roughly a third of the total Australian population. Of these, 5.2% of this population identify as Aboriginal and/or Torres Strait Islander people [47].

Data sources and linkage

De-identified demographic, clinical and administrative data relating to appointment scheduling and attendance were extracted from the patient database of the state-funded clinical genetic health service in each state: the Northern Territory Genetics Service (Microsoft Excel, for years 2014-2018), Genetic Services of Western Australia (KinTrak, for years 2015-2018), and Genetic Health Queensland (KinTrak, for years 2015-2017). Patients' Aboriginal status was not recorded in the Genetic Services of Western Australia's internal patient database and was therefore extracted from the overarching hospital service's electronic medical record system (Topaz, King Edward Memorial Hospital, Subiaco) by cross-matching patient hospital record numbers which was recorded in both databases. For population denominators, census data were retrieved from the Australian Bureau of Statistics (ABS) [47].

Variable definitions

Data were complete for most variables, except for Aboriginal and/or Torres Strait Islander status and remoteness.

'Aboriginal and/or Torres Strait Islander' denotes people who self-identified (or were identified by a guardian) as Aboriginal and/or Torres Strait Islander either during their clinical genetic health consultation or on intake to the hospital system. A binary indicator of 'Aboriginal and/or Torres Strait Islander person' and 'non- Aboriginal and/or Torres Strait Islander person' was created. We recognise that this dichotomy is a socio-cultural construct that reduces people of over 250 first nations to a single identity. It is a construct that does not represent biological differences, and that both designations represent diverse and genetically heterogenous populations. In Western Australia, 19.7% of patients (2,247 people) did not have Aboriginal and/or Torres Strait Islander status recorded in hospital records and these individuals were excluded from analysis, while this variable was complete for the Northern Territory and Queensland.

Remoteness was coded by matching each patient's residential postcode to the Australian Bureau of Statistics (ABS) recognised Australian Statistical Geography Standard (ASGS) remoteness structure. The ASGS remoteness structure was further coded from five into three categories of – 'Major City'; 'Regional', which included inner and outer regional; and 'Remote', which included remote and very remote ASGS classifications [48].

Age was calculated on the date of a patient's first scheduled appointment from date of birth and stratified into 10-year age groups for analysis. Gender was collected as a binary 'male' or 'female' on basis of self-report (or by guardian).

Appointment location was recorded as in-person at clinic (which included both clinics conducted in major centres and outreach clinics conducted in Aboriginal and/or Torres Strait Islander communities) or as telehealth.

The suspected or known reason for referral to the clinical genetic health service was coded as 'rare disease' or 'cancer'. Prenatal referrals were a subcategory of 'rare disease'.

Determination of outcomes

Appointment scheduling and appointment attendance were the outcomes of interest. Scheduling of appointment denoted an individual had an appointment scheduled in a clinical genetic health service database. Appointment attendance reflected whether the first scheduled appointment was attended (as opposed to cancelled, re-scheduled, or not attended).

Statistical analysis

Statistical analysis was conducted using SPSS 27 (SPSS Inc., Chicago, Illinois, USA), with exception of relative risk and rate ratios, which were calculated using Medcalc online (Medcalc software, Ostend, Belgium) and

Multivariate Poisson Regression which was modelled using Stata 16 (StatCorp, College Station, Texas, USA). Microsoft Excel was used to tabulate data including incident appointment scheduling and attendance.

To make comparisons with non-Aboriginal and/or Torres Strait populations, rate ratios were used as a relative measure of inequity and rate difference as an absolute measure. For categorical data, 2-sided Pearson c^2 tests were used to assess trends in proportions attending appointments attended.

Incidence rates for appointment scheduling were calculated using ABS census data. For population denominators, tables with Aboriginal status, age, gender and state population counts were retrieved from the ABS website [47]. Incidence rates have been presented as annual incidence per 100,000 people as most genetic conditions are individually rare. Rate of attendance was calculated as percent of those with a scheduled appointment who attended.

Multivariate Poisson Regression was used to measure inequity in appointment scheduling and attendance. For appointment scheduling, a frequency weight variable was used, and results expressed as an Incident Rate Ratio (IRR). Both models included adjustment for age, gender, and state.

Declarations

Availability of data and materials

he three administrative datasets that support findings in this study are available from the participating Clinical Genetic Health Services, but strict restrictions apply to the availability of these data, which were used only with ethical clearance and endorsement by services. These data are not publicly available. Australian Census Datasets used in the current study are available from the Australian Bureau of Statistics repository, [https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/latest-release#data-download].

Code availability

Not applicable, data are not publicly available.

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Author contributions

JL designed and performed epidemiological analyses and wrote the manuscript. MK co-conceptualised the overall study of which this research forms a part with RS, as well as input from YP. MK also led the acquisition of funding and provided statistical advice. PD oversaw administration of the project and performed data collection and management. PD, MK and GB assisted with drafting the manuscript. The study was facilitated by GB in Western Australia, LT and CAS in the Northern Territory and ASF in Queensland. RS, JMc, LM, GG, EK, HD, MJ, YP, GP and GB were involved in design of the study and/or contributed to funding acquisition. All authors reviewed and provided either comments or edits on the manuscript.

Competing interests statement

RS was the Director of the Northern Territory Genetics Service between 2010-20. CAS commenced as Director of the Northern Territory Genetics Service in 2021. GB is a consultant clinical geneticist at Genetics Services of Western Australia and JMc is the Director of Genetic Health Queensland. HD was the Director of the Office of Population Health Genomics, Public and Aboriginal Health Division, Government of Western Australia until Nov 2018.

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Tables

Table 1: Characteristics of people scheduled an appointment, by Aboriginal and/or Torres Strait Islander status

	Aboriginal and/or Torres Strait	non-Aboriginal and/or Torres

	Islander people (annual n = 182)			Strait Islander (annual n = 4103)			
	n	(%)	95%CI	n	(%)	95%CI	p-value
Age							
0-9	83	45.7	(38.5-53.0)	859	20.9	(19.7-22.2)	<0.001
10-19	28	15.6	(10.3-20.8)	355	8.6	(7.8-9.5)	
20-29	21	11.6	(6.9-16.2)	531	12.9	(11.9-14.0)	
30-39	20	10.8	(6.3-15.3)	788	19.2	(18.0-20.4)	
40-49	11	6.2	(2.7-9.7)	589	14.4	(13.3-15.4)	
50-59	18	10.0	(5.6-14.3)	981	23.9	(22.6-25.2)	
Gender							
Female	103	56.5	(49.2-63.6)	2733	66.7	(65.2-68.1)	<0.001
Male	79	43.5	(36.1-50.5)	1363	33.3	(31.8-34.7)	
Remoteness							
Major city	70	40.5	(33.1-47.8)	3062	77.1	(75.8-78.4)	<0.001
Regional	66	38.2	(30.9-45.4)	776	19.5	(18.3-20.8)	
Remote	37	21.4	(15.3-27.5)	135	3.4	(2.8-4.0)	
Referral by							
GP	31	19.8	(13.6-26.1)	1124	31.4	(29.9-32.9)	<0.001
Specialist	107	69.0	(61.8-76.4)	1950	54.4	(52.8-56.0)	
Other	17	11.2	(6.3-16.2)	510	14.2	(13.1-15.4)	
Location of service							
Clinic	129	94.0	(90.0-98.0)	3991	97.3	(96.8-97.8)	<0.001
Telehealth	8	5.8	(1.9-9.8)	112	2.7	(2.2-3.2)	
Reason							
Rare disease	109	75.7	(68.7-82.7)	1796	56.0	(54.3-57.7)	<0.001
Cancer	35	24.3	(17.3-31.3)	1410	44.0	(42.3-45.7)	<0.001
Prenatal	1	0.7	(0-2)	125	3.1	(2.5-3.6)	<0.001

Table 2: Characteristics of Aboriginal and/or Torres Strait Islander people scheduled an appointment, by State

	Queensland (2015-17) n=216 (annual n =72)			Northern Territory Total (2014-2018) (annual=182) n=148 (annual n =30)			Western Australia (2015-18) n=320 (annual n =80)			
	%	(95%CI)		%	(95%CI)		%	(95%CI)		
	n			n			(%)	95%CI		p-value
Age										
0-9	62.2	(54.3-70.0)		50.6	(45.1-56.1)					
33.8	(27.5-40.1)		83	45.7			(38.5-53.0)			<0.001
10-19	15.5	(9.7-21.4)		15.9	(11.9-19.9)					
15.3	(10.5-20.1)		28	15.6			(10.3-20.8)			
20-29	10.1	(5.3-15.0)		9.7	(6.4-12.9)					
14.4	(9.7-19.0)		21	11.6			(6.9-16.2)			

30-39		5.4	(1.8-9.0)		12.5	(8.9-16.1)	
11.1	(6.9-15.3)	20	10.8			(6.3-15.3)	
40-49		6.1	(2.2-9.9)		4.7	(2.4-7.0)	
7.9	(4.3-11.5)	11	6.2			(2.7-9.7)	
50-59		0.7	(0-2.0)		6.6	(3.8-9.3)	
17.6	(12.5-22.7)	18	10.0			(5.6-14.3)	
Gender							
Female		54.4	(46.4-62.5)		53.8	(48.1-59.0)	
60.6	(54.1-67.2)	103	56.4			(49.2-63.6)	
0.259							
Male		45.6	(37.5-53.6)		46.3	(41.0-51.9)	
39.4	(32.8-45.9)	79	43.3			(36.1-50.5)	
Remoteness							
Major city					50.0	(44.4-55.6)	
47.5	(40.7-54.4)	70	40.7			(33.3-48.0)	
<0.001							
Regional		54.5	(46.4-62.6)		23.7	(18.9-28.5)	
47.5	(40.7-54.4)	66	38.2			(31.0-45.5)	
Remote		45.5	(37.4-53.6)		26.3	(21.4-31.3)	
4.9	(1.9-7.9)	37	21.1			(15.0-27.2)	
Referral by							
GP		4.1	(0.9-7.2)		10.1	(6.3-13.8)	
36.6	(29.8-43.5)	31	16.9			(11.5-22.4)	
<0.001							
Specialist		94.6	(91.0-98.2)		62.5	(56.5-68.5)	
63.4	(56.5-70.2)	107	58.8			(51.7-66.0)	
Other		1.4	(0-3.2)		27.4	(21.9-33.0)	
-		17	9.6			(5.3-13.8)	
Reason							
Rare disease		88.5	(83.2-93.8)		80.9	(75.2-86.5)	
67.5	(61.1-73.9)	109	59.9			(52.7-67.0)	
<0.001							
Prenatal*		0.7	(0-2.0)		0.3	(0-0.9)	
1.9	(0.1-3.6)	2	1.0	(0-2.4)		0.156	
Cancer		11.5	(6.2-16.8)		19.1	(13.5-24.8)	
32.5	(26.1-38.9)	35	19.0			(13.3-24.7)	
<0.001							

*Prenatal

Table 3: Equity in annual appointment scheduling for Aboriginal and/or Torres Strait Islander (univariate analysis)

Difference		Aboriginal and/or Torres Strait Islander			Non Aboriginal and/or Torres Strait Islander		
Rate ratio (95% CI)		Aboriginal and/or Torres Strait Islander			Aboriginal and/or Torres Strait Islander		
		n	Incident referral per 100000 (95%CI)	Expected referral (n)	n	Incident referral per100000 (95%CI)	under-referred (%)
Age							
0-9		83	90 (71-110)		859	92 (86-98)	
0.98	(0.79-1.23)	84		1.2			
10-19		28	34 (22-47)		355	41 (37-45)	
0.83	(0.57-1.22)	34		17.6			

20-29			21	31 (18-44)			531	51 (47-55)	
0.60	(0.39-0.92)	35			40.0				
30-39			20	40 (22-57)			788	77 (71-82)	
0.52	(0.34-0.82)	38			47.4				
40-49			11	25 (10-40)			589	59 (54-64)	
0.42	(0.23-0.76)	26			57.7				
50+			18	31 (17-45)			981	41 (39-44)	
0.75	(0.47-1.19)	24			25.0				
Gender									
Female			103	52 (42-61)			2733	75 (72-78)	
0.69	(0.57-0.84)	149			30.9				
Male			79	40 (11-36)			1363	38 (36-40)	
1.06	(0.85-1.33)	74			-6.8				
Remoteness									
Major city			70	61 (46-75)			3062	62 (60-64)	
1.02	(0.81-1.29)	72			2.8				
Regional			66	44 (34-55)			776	38 (35-41)	
0.85	(0.66-1.10)	56			-17.9				
Remote			37	38 (19-37)			135	54 (45-63)	
1.92	(1.33-2.76)	71			47.9				
State									
NT			30	40 (26-55)			115	67 (55-79)	
0.60	(0.40-0.89)	50			40.0				
WA			80	80 (62-97)			2330	95 (91-99)	
0.84	(0.67-1.05)	95			15.8				
QLD			72	33 (25-40)			1658	36 (34-38)	
0.91	(0.72-1.15)	79			8.9				
Reason									
Rare disease			109	27 (22-33)			1796	25 (24-26)	
1.11	(0.92-1.35)	98			-11.2				
Cancer			35	9 (6-12)			1410	19 (18-20)	
0.45	(0.32-0.64)	77			54.5				
Prenatal			2	1 (0-3)			125	4 (4-5)	
0.28	(0.07-1.14)	7			71.4				
TOTAL			182	46 (39-52)			4103	57 (55-58)	
1.23	(1.06-1.43)				224	19.2			

Table 4: Equity in annual attendance for Aboriginal and/or Torres Strait Islander people (univariate analysis)

Difference			Aboriginal and/or Torres Strait Islander			Non Aboriginal and/or Torres Strait Islander		
			n	%	95%CI	n	%	95%CI
		% difference			Rate ratio (95% CI)			
Age								
0-9			63	76.3	(67.1-85.4)	720	83.8	(81.4-86.3)
7.6	0.91				(0.80-1.03)			
10-19			20	70.1	(53.2-86.9)	289	81.6	(77.5-85.6)
11.5	0.86				(0.69-1.11)			
20-29			14	68.1	(48.2-88.0)	465	87.5	(84.7-90.4)
19.5	0.76				(0.56-1.03)			
30-39			16	79.4	(61.5-97.3)	690	87.5	(85.2-89.9)
8.1	0.91				(0.73-1.14)			

40-49	9	76.7	(51.9-100)	521	88.5	(85.9-91.0)	11.8	0.85	(0.61-1.18)
50+	15	80.3	(65.7-100)	863	87.9	(85.9-90.0)	4.9	0.95	(0.77-1.17)
Gender									
Female	80	78.2	(70.2-86.2)	2376	86.9	(85.7-88.2)	8.7	0.90	(0.81-1.00)
Male	57	71.6	(61.7-81.5)	1167	85.6	(83.8-87.5)	14.0	0.80	(0.69-0.91)
Remoteness									
Major city	51	71.1	(65.5-76.7)	2649	86.5	(85.3-87.7)	13.7	1.19	(1.03-1.37)
Regional	52	79.3	(69.5-89.0)	666	85.9	(83.5-88.4)	6.7	1.09	(0.96-1.24)
Remote	27	72.9	(58.4-87.3)	108	80.0	(73.2-86.7)	7.1	1.10	(0.89-1.36)
State									
NT	30	76.7	(61.5-91.8)	108	94.3	(90.0-98.5)	17.6	0.82	(0.67-1.00)
WA	80	65.0	(54.5-75.5)	1855	79.6	(78.0-81.2)	14.6	0.82	(0.67-1.00)
QLD	72	86.1	(78.1-94.1)	1585	95.6	(94.6-96.6)	9.5	0.82	(0.69-0.96)
Reason									
Rare disease	85	78.2	(70.4-85.9)	1562	87.0	(85.4-88.5)	8.8	0.90	(0.81-0.99)
Cancer	26	74.9	(60.4-89.4)	1261	89.4	(87.8-91.0)	14.5	0.83	(0.68-1.01)
Prenatal	2	100.0		114	98.6	(96.5-100)	-1.4	1.10	(1.04-1.16)
Total attended	137	75.4	(69.1-81.6)	4103	86.5	(85.4-87.5)	11.1	0.87	(0.80-0.95)

Table 5: Equity in appointment scheduling, multivariate analysis using Poisson regression

	Incident Risk ratio	95%CI	p-value
Appointment scheduling			
Aboriginal and/or Torres Strait Islander person			
No (ref)	1.00		
Yes	0.73	(0.68-0.80)	<0.001
Male	0.51	(0.50-0.53)	<0.001
Age group			
0-9 years (ref)	1.00		
10-19 years	0.43	(0.41-0.46)	<0.001
20-29 years	0.50	(0.48-0.53)	<0.001
30-39 years	0.74	(0.70-0.77)	<0.001
40-49 years	0.57	(0.54-0.60)	<0.001
50+ years	0.41	(0.39-0.43)	<0.001
State			
Queensland (ref)	1.00		
Northern Territory	2.85	(2.63-3.08)	<0.001
Western Australia	3.47	(3.35-3.59)	<0.001
Attendance			
Aboriginal and/or Torres Strait Islander			

	No (ref)	1.00		
	Yes	0.85	(0.78-0.93)	<0.001
Male		1.00	(0.96-1.04)	<0.952
Age group				
	0-9 years (ref)	1.00		
	10-19 years	0.95	(0.89-1.02)	<0.138
	20-29 years	1.00	(0.94-1.07)	<0.935
	30-39 years	1.01	(0.96-1.07)	<0.723
	40-49 years	1.00	(0.94-1.07)	<0.918
	50+ years	1.00	(0.95-1.05)	<0.894
State				
	Queensland	1.00		
	Northern Territory	0.98	(0.90-1.06)	<0.592
	Western Australia	0.83	(0.80-0.86)	<0.001

Figures

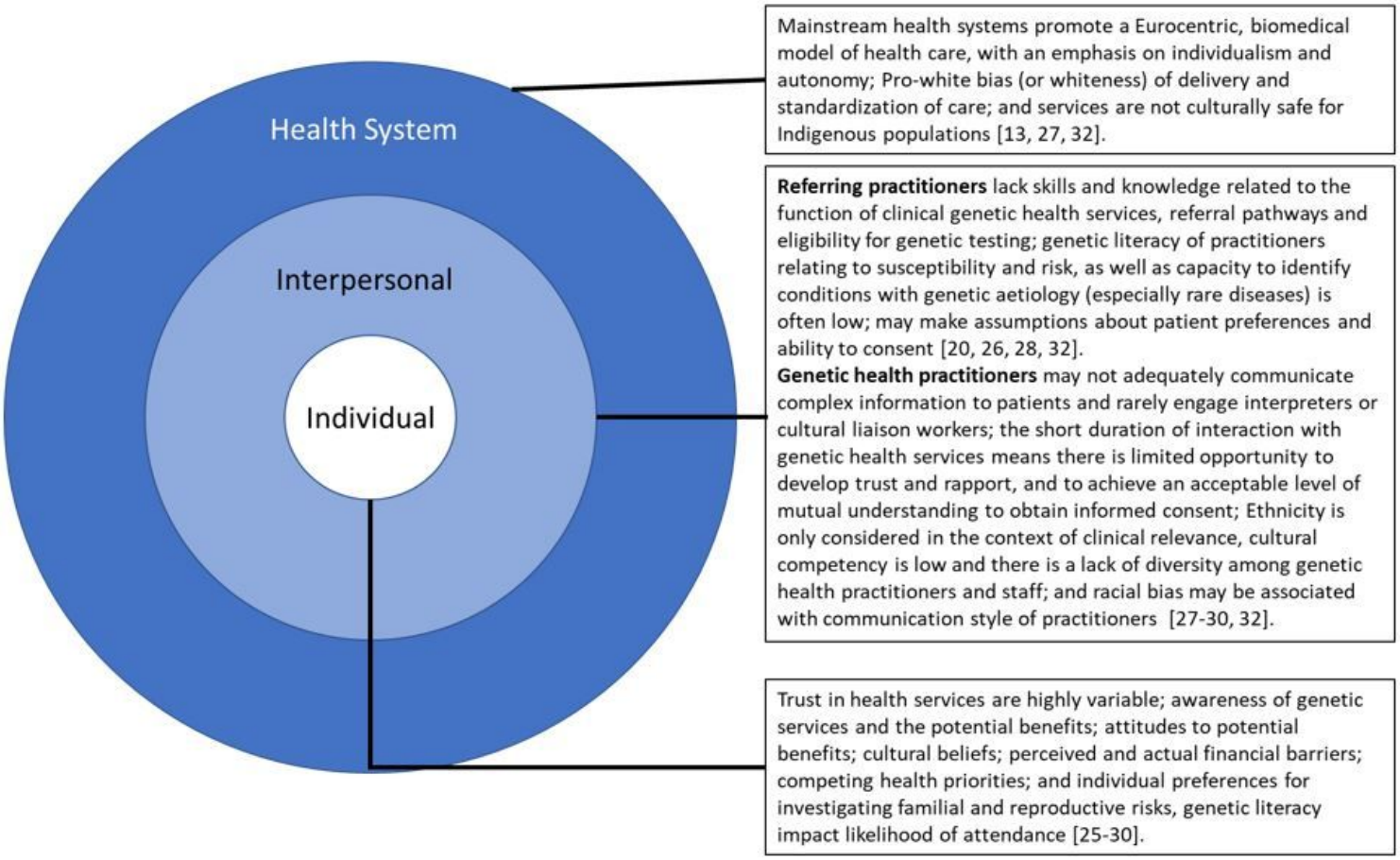

Figure 1

An ecological framework presenting reasons for inequity across the levels of individual, interpersonal and health system.

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