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**Better Indigenous Genetic (BIG) Health Services**

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**Objectives/aims**

Genetic health services are playing an increasingly important role in improving human health. Aboriginal and Torres Strait Islander people are underrepresented in such services despite having higher prevalence of a number of genetically determined conditions and evidence of willingness to access these services. This project asks what strategies can be put in place to improve the delivery of genetic health services to Aboriginal and Torres Strait Islander people living in the Northern Territory (NT), Western Australian (WA) and Queensland (QLD). To determine this, the research will investigate the key barriers and facilitators to effective, culturally competent delivery of genetic services for Aboriginal and Torres Strait Islander patients. It will also seek to examine the quality, acceptability and effectiveness of current models of genetic health service provision, thereby gaining insights into best practice and feasibility.

The first National Health Genomics Policy Framework was released in 2017 and is testament to the perceived potential of genomics to transform clinical practice and health outcomes. There is a strong focus on equity in the National Health Genomics Policy Framework 2018-2021 however, for this is to be achieved, genetic services need to be delivered to Aboriginal and Torres Strait Islander people in an accessible and culturally appropriate way. The BIG Health Services project will add a body of evidence to this program and policy area and seek to reduce inequities in who will gain from the health benefits that personalised medicine can offer.

**Methods**

The research is designed to take an open, unbiased and objective approach to explore, alongside Aboriginal and Torres Strait Islander people, what the experienced barriers and facilitators are in accessing genetic services. Through semi-structured interviews with key informants, the research explores issues such as: awareness of services; people's reasons for accessing or wanting to access these services; what advice is given to people; genetic literacy associated with the information people are given and the implications of this; and dimensions of access such as coordination of care and supporting services. Interviewing across each of the four models will enable the comparison of the experiences of different stakeholder groups and examine how well the different service delivery models meet the needs of users. The BIG Health Services is taking a mixed-method approach, with the qualitative interview data to be strengthened through a quantitative audit of genetic service provider databases investigating service utilization trends including patterns in attendance, appropriate referrals and follow up.

Workshops are held throughout the project lifespan to bring together the Governance members, which comprises of the research team (approximately 45% Indigenous), the Project Reference Group (approximately 50% Indigenous), and the End User Group (100% Indigenous). The purpose of the workshops is to refine project directions, discuss findings and, once all data analysis is complete, another workshop will be held to develop recommendations.

**Main findings**

Consultations with medical services, research initiatives and primary care clinics that service communities across Australia has revealed a significant lack of awareness of what genetic services are offered, the health benefits they can bring and possible applications. Despite the high burden of chronic disease and the significant contribution that epigenetics and genetics play in these conditions, genetics is viewed as a low priority. Aboriginal and Torres Strait Islander people are significantly underrepresented in clinical genetic services, by approximately 50% in the Northern Territory, and the vast majority of referrals come from urban specialists.

Data collection is under way to gather information from Aboriginal and Torres Strait Islander users of the genetic services on the experienced barriers and facilitators to accessing these services. This presentation will explore some of the key challenges in the provision of culturally accessible genetic services for Aboriginal and Torres Strait Islander people from the perspective of different stakeholders along the clinical genetics care pathway.