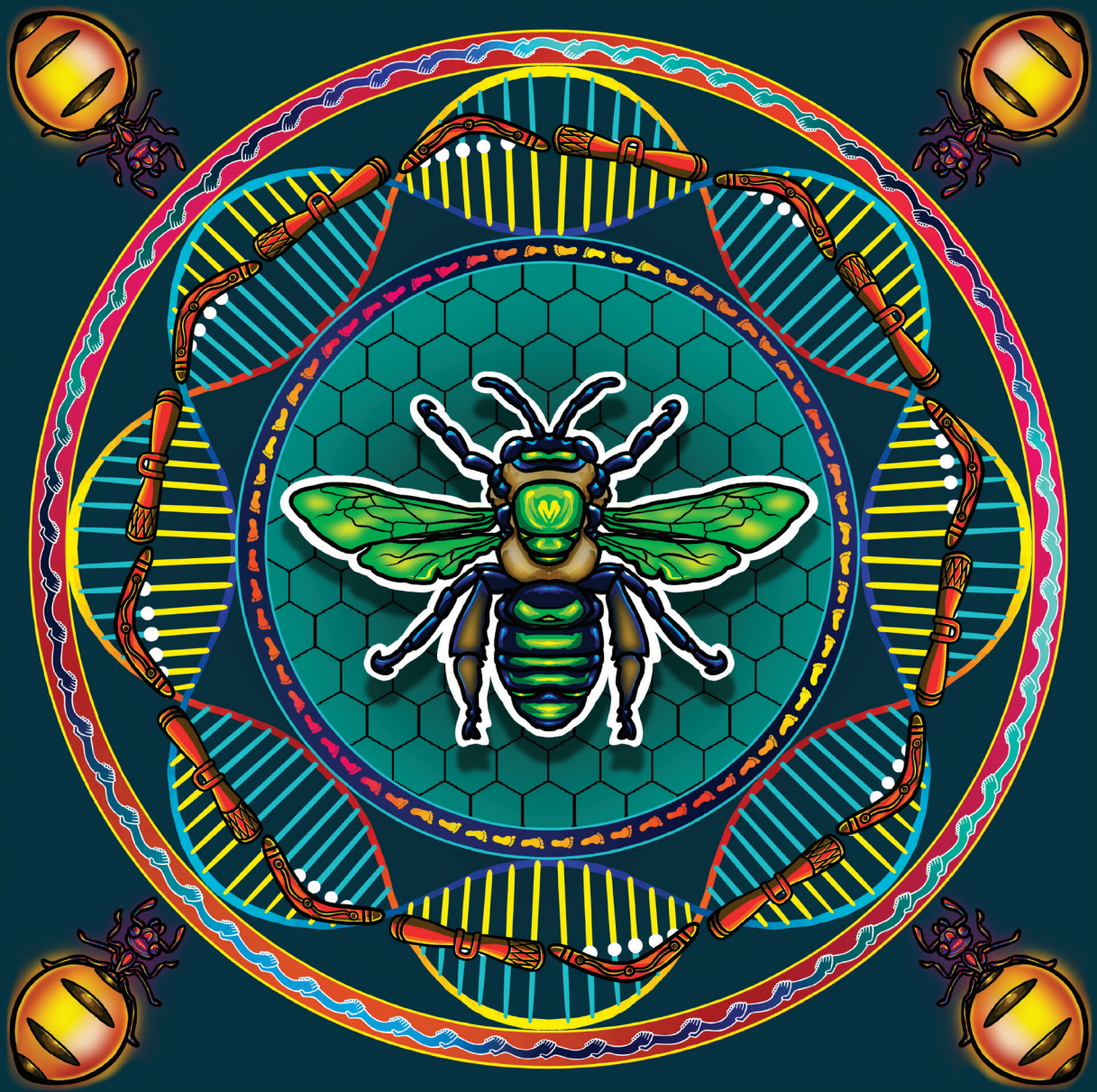
INTEGRATED GENETIC HEALTH CARE

Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership



QIMR Berghofer

Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership

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QIMR Berghofer

QAIHC
Queensland Aboriginal and Islander Health Council

Queensland Government

Queensland Genomics

ACKNOWLEDGEMENT

We acknowledge the traditional custodians of Australia, Aboriginal and Torres Strait Islander peoples and pay respect to Elders past, present and future.

We acknowledge the people, organisations and communities who have contributed to the development of this document, Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership.

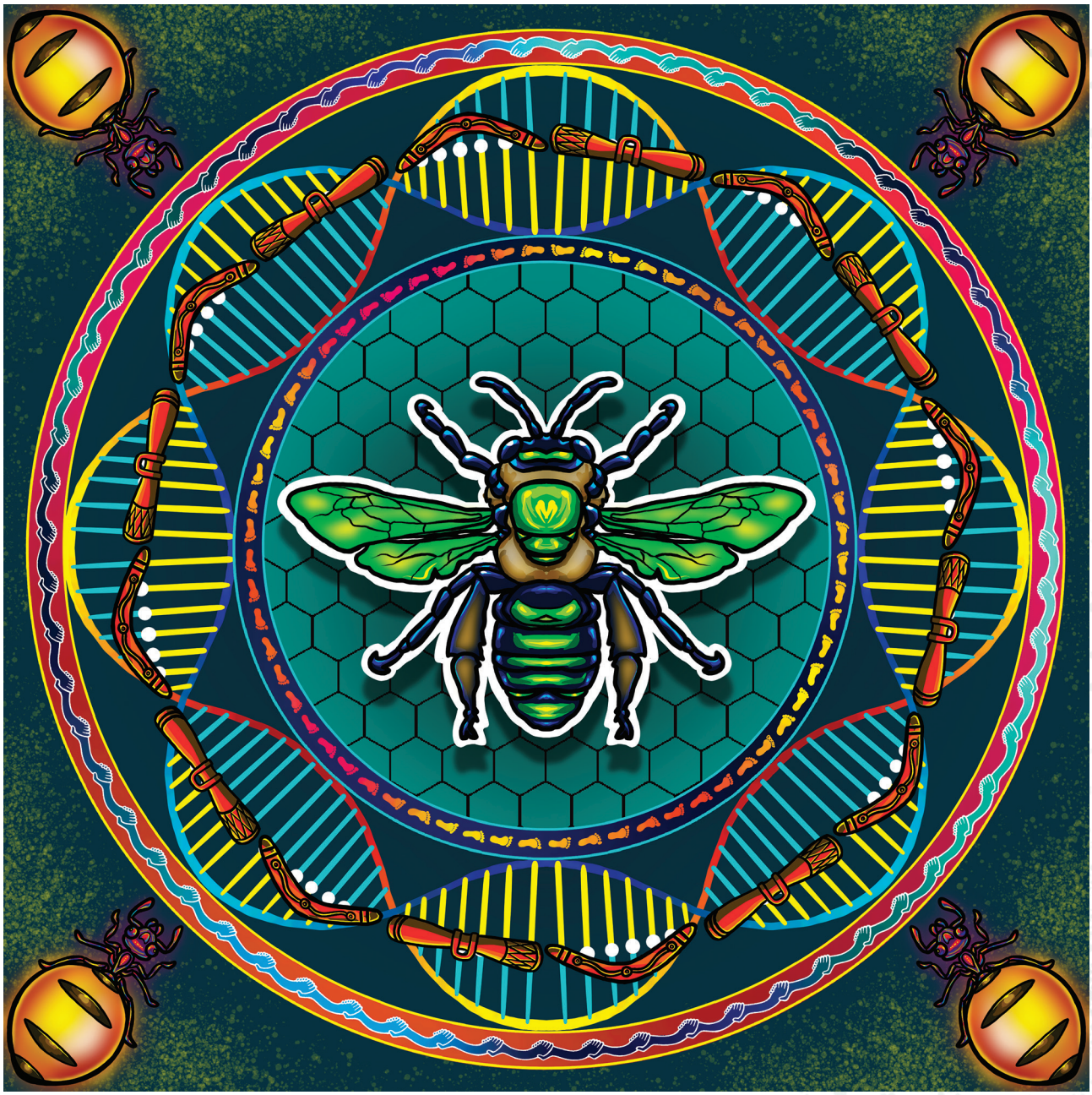
TERMINOLOGY

In this document, the term Indigenous Australians and First Nations peoples are used interchangeably with the terms Aboriginal and Torres Strait Islander peoples; we acknowledge these terms are used for both traditional custodians of Australia – Aboriginal peoples and Torres Strait Islander peoples. No disrespect is intended, and we acknowledge the rich cultural diversity of the peoples who are the custodians of the land with which they identify and with whom they share a connection and ancestry.

ARTWORK DESCRIPTION

Healing Pathways by Luke Mallie

The collaboration of the project is observed by incorporating the spirit of the native Australian bee, within a hive of productivity and integrated teamwork, everyone comes together to nurture and protect a lifecycle of community and healing. Referral Pathways is a care model developed with Aboriginal and Torres Strait Islanders Queenslanders, with a strong respect for culture and traditional ways, represented in the artwork through the symbols of the boomerang (a tangible link for Aboriginal people to the land), and the Torres Strait Islander drum (an instrument to preserve and communicate knowledge through generations). The cultural significance of First Nations peoples is preserved in many ways and integrated into the project at every level. Healing Pathways shows both hands and feet, as pathways and connections are created, a commitment to heal one another through a journey of genetic health and improved access for Aboriginal and Torres Strait Islander peoples. The ant is a universal symbol of community strength and ties together the foundations of this Genetic Health Services project.



FOREWORD

QIMR Berghofer Medical Research Institute

Reducing the impact of disease and closing the gap in life expectancy for Aboriginal and Torres Strait Islander Australians is a priority nationally, for Queensland and for the QIMR Berghofer Medical Research Institute. We recognise the rights of Aboriginal and Torres Strait Islander peoples to self-determine, celebrate their diversity, and to have their sovereignty acknowledged. We recognise that while we refer to Aboriginal and Torres Strait Islander peoples in a collective fashion, pre-European colonisation there were numerous and diverse nations across this continent. We acknowledge that these nations celebrated a responsibility for, and connection with, land, water, air and nature and as the oldest living cultures on the planet.

As a statutory entity for medical research in Queensland and with a responsibility to empower Queenslanders with health through medical research, we promise to use our expertise, influence and capabilities to support Aboriginal and Torres Strait Islander leadership. We commit to work with partners and the community to realise a promise of health equity.

Research in genomics and genetics continue to rapidly gain momentum in the exploration of precision diagnostics and treatment. This publication represents a culmination of four years of work across Queensland in collaboration with communities, health service, research, ethics and academic experts. I am proud to celebrate this work as a flagship program that recognises the potential for partnership in translating medical research for a real-world impact. I look forward to supporting an ongoing conversation with stakeholders, partners and leaders that recognises opportunities for medical research to inform and conversely to be informed.



Professor Fabienne Mackay
Director and CEO
QIMR Berghofer Medical Research Institute

Genetic Health Queensland

Genetic Health Queensland is proud to provide genetic services to all Queenslanders. As a state-wide service, GHQ is committed to providing service delivery across the whole state including rural and remote regions. Ensuring Aboriginal and Torres Strait Islander Queenslanders also have access to culturally-appropriate genetic care is a priority.

This project, in undertaking codesign for a genetics referral pathway, in partnership with Queensland Aboriginal and Islander Health Council (QAIHC), and QIMR Berghofer, is a key part of developing better engagement. I would like to acknowledge the Queensland government for their investment in this project.

Integrating coordinated care across Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs) to support referrals to GHQ will promote equity of access for Aboriginal and Torres Strait islander peoples. There will be shared learning regarding genetics, genomics and the cultural needs of the population, leading to improved health outcomes.

The project has shown great promise in engaging with and developing a referral pathway across Queensland within the health and community sector and we look forward to building on this work.



Professor Julie McGaughran
Director, Genetic Health Queensland

QIMR Berghofer

Queensland Aboriginal and Islander Health Council

The Queensland Aboriginal and Islander Health Council (QAIHC), would like to acknowledge the Federal and Queensland governments for their significant investments embedding genomics within the context of Aboriginal and Torres Strait Islander healthcare. QAIHC also acknowledge the synergy of collaboration and co-design between QIMR, Genetic Health Queensland and our stakeholders.

As an emphasis of implementing genomics into primary healthcare continues, there is potential to integrate coordinated care across Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs), improving health outcomes for our mob in Queensland.

This research is vital in contributing knowledge to build an evidence base for improved health service delivery that benefits and ensures access to equitable health opportunities for Aboriginal and Torres Strait Islander Queenslanders.

QAIHC remain eager to continue our role facilitating information, stakeholders, and community voices as we co-design and rewrite the future of Aboriginal and Torres Strait Islander Queenslanders.



Cleveland Fagan,
CEO, Queensland Aboriginal and Islander Health Council.

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EXECUTIVE SUMMARY

The Federal and Queensland governments have made a significant investment to embed genomics into healthcare.[1] With a growing emphasis on implementation of genomics into primary healthcare,[2] there is potential that not ensuring coordinated care across the primary and specialist service sector will contribute to widening the gap in healthcare access and consequently, health outcomes for Aboriginal and Torres Strait Islander peoples in Queensland.

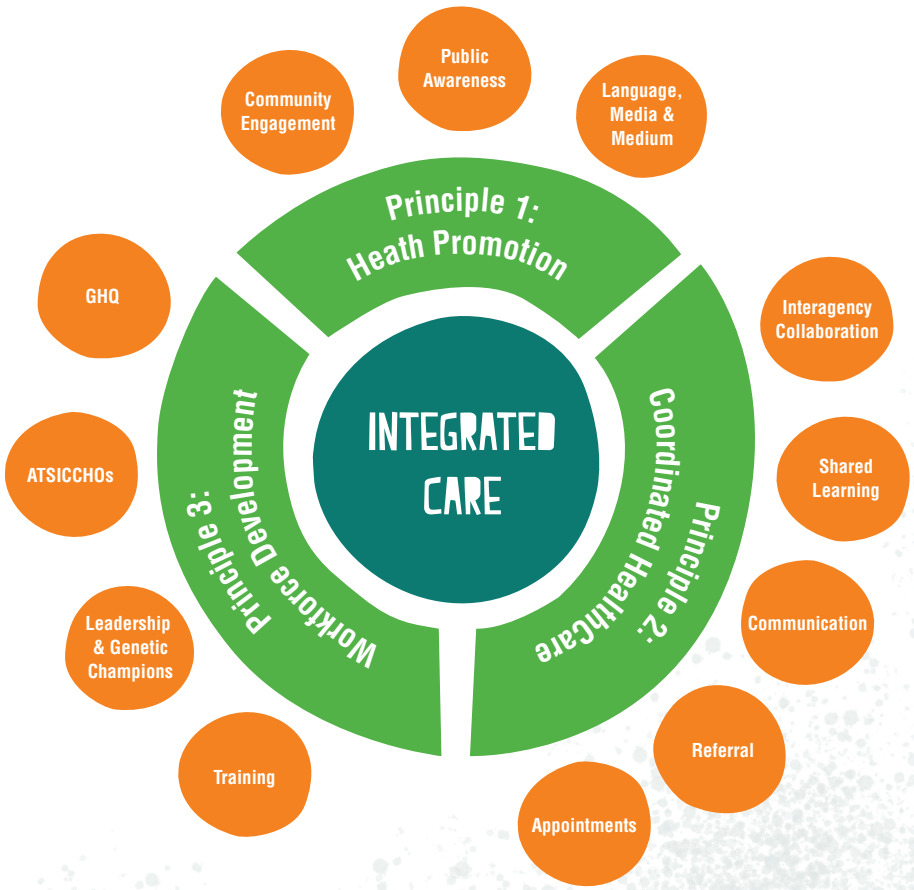
To ensure integration and benefits for Aboriginal and Torres Strait Islander peoples, this co-designed document reflects a preferred integrated healthcare model and referral pathway for improved access to genetic health services for patients of ATSICCHOs (primary healthcare provider) and Genetic Health Queensland (tertiary health care provider).

Development of the *Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership* explored service utilisation and workforce needs and preferences with Aboriginal and Torres Strait Islander stakeholders, communities and champions across Queensland. Topics discussed though a series of workshops included:

- engaging community
- pathways for genetic health access
- promotion and access.

Throughout workshops, stakeholders were able to relay key messages, identify and describe barriers, and make recommendations about the three principles; health promotion, coordinated healthcare and workforce development. Themes were drawn upon within each principle. Each theme highlights key messages, barriers and recommendations where appropriate.

Figure 1: Integrated Genetic HealthCare Principles and Themes



PURPOSE AND SCOPE

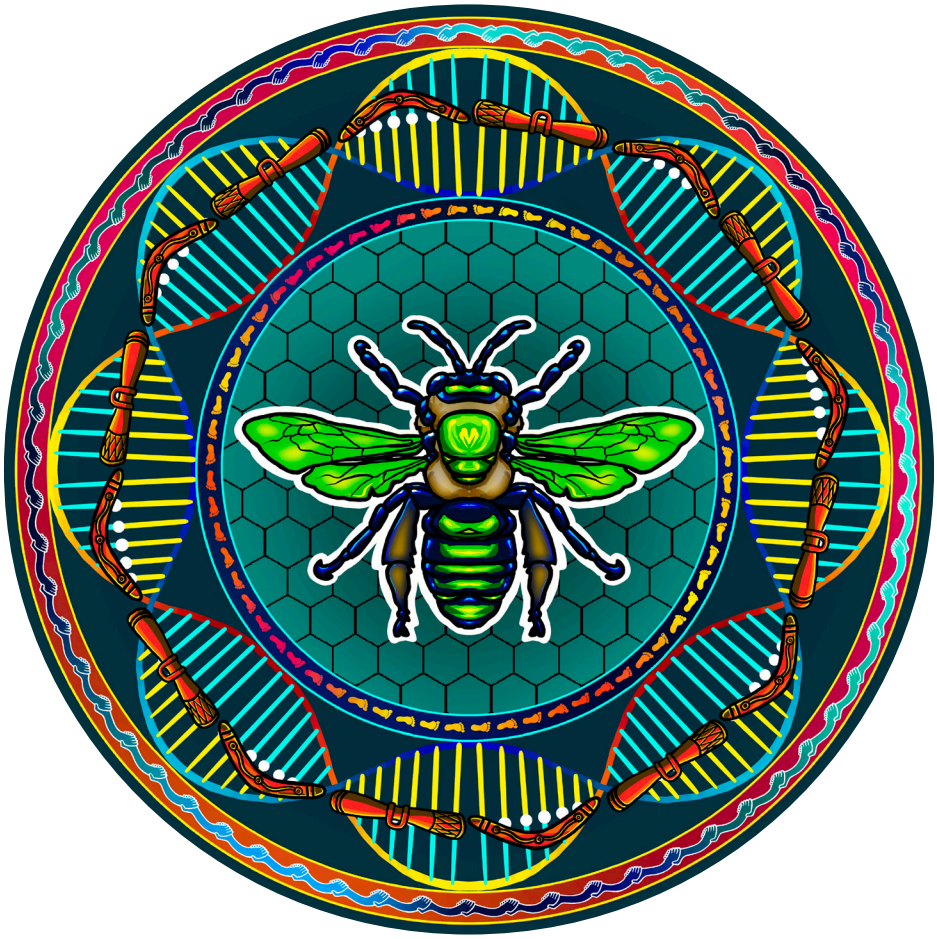
In developing *Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership,* we aim to describe culturally safe and appropriate integrated healthcare and referral pathways to support and improve access for Aboriginal and Torres Strait Islander peoples to clinical genetic services.

Findings of the project will contribute knowledge to build an evidence base for improved health service delivery that benefits and ensures access to equitable health opportunities for Aboriginal and Torres Strait Islander Queenslanders.

The *Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership* project came about through work with communities across Queensland about their needs and preferences with respect to genomics and genetic health care.[3,4]

Our consultation methodology (Appendix 1) allowed us to identify, consult and engage with stakeholders from the community and ATSICCHOs. Our workshops were underpinned by the principles:

- community engagement
- partnership
- Aboriginal and Torres Strait Islander leadership
- person-centered care
- co-design
- self determination
- relationships and trust.



BACKGROUND

i. Clinical Genetics and Genetic Health Queensland

Genomics is a relatively new technology in healthcare. Genomic medicine has the potential to transform how health care is delivered. It promises a more efficient health system through rapid diagnosis, early intervention, prevention, and targeted therapy for genetic conditions, leading to improved patient outcomes. The successful application of this technology will contribute to a precise approach to health care. There are several challenges to integrating genomics. The social, ethical and cultural aspects are just as important as the science. Consent is a cornerstone of the clinical service that delivers genomic testing as part of its care. Clinical genetics services have expertise in the provision of genetics services and genomic testing.

Genetic Health Queensland

In Queensland, there is a single, state-wide public service delivering clinical genetics services, Genetic Health Queensland (GHQ). GHQ opened in 1995 and since 2008 operated from the Royal Brisbane and Women's Hospital (RBWH). Services are delivered by a team comprising of clinical geneticists, genetic counsellors and administrative staff. GHQ provides diagnosis, counselling and management advice to individuals and families who have or are at risk of a genetic or inherited condition.

GHQ delivers clinical services in two modes, virtual and face-to-face, according to the clinical needs for each patient. As part of GHQ's state-wide service, genetic counsellors are permanently located across Queensland. In addition, GHQ's clinical geneticists provide outreach clinics for patients from regional townships.

To access GHQ the patient must be referred by a doctor (either a GP or specialist) to the Metro North Central Patient Intake Unit. Clinicians wanting more information about who can and should be referred, can access GHQ's Clinical Prioritisation Criteria (CPC) via the GHQ website or by calling the service and speaking with one of the clinicians.[5]

GHQ accepts referrals for a range of conditions which can be classified into four areas.

1. Prenatal

Patients with a family history of a genetic condition are at risk of having a child with a genetic condition or who are carrying a child with a suspected genetic condition; seek counselling or genetic testing during a pregnancy.

2. Paediatric

Babies and children with medical and developmental issues for whom a genetic cause is suspected or possible. Common conditions referred include congenital anomalies or structural differences, developmental delay, or intellectual impairment, suspected syndromic or inherited disorders of the senses (hearing and vision), genetic disorders of the muscles and nervous system and paediatric cancers that may have a genetic or inherited basis. Children are seen to aid in diagnosis or to provide further assessment and advice where a diagnosis has already been made. Families will be counselled on the inheritance pattern, chance of recurrence in future pregnancies and options available to reduce these chances where appropriate.

3. Adult – General

Adults with either known or suspected heritable conditions such as certain cardiac and renal conditions. For these individuals, the risks to their family or future offspring can be addressed and management advice provided. GHQ also see individuals for adult-onset disorders, which do not become apparent until an older age. Patients at risk of developing a condition due to their family history are supported to discuss the implications for themselves and their family and, if the causative genetic factor has been identified in that family, to discuss the option of genetic testing. This is referred to as predictive genetic testing.

4. Adult – Cancer

Individuals with a personal or strong family history of cancer are seen to determine if the cancer is likely to have a heritable basis. Individuals are advised of their risk of developing cancer in the future based on their family history and/or genetic status and recommendations are made regarding an appropriate cancer surveillance program. If a genetic factor responsible for an increased cancer risk has been identified in the individual's family, predictive testing can also be provided.

Clinical services are delivered by clinical geneticists and genetic counsellors. A clinical geneticist is a medical doctor specialised in diagnosing patients and families who have or are at-risk of a genetic condition. Clinical geneticists help identify families at risk of a genetic condition by assessing the patient's physical features, medical history, gathering and analysing family history and inheritance patterns to calculate chances of recurrence. They provide information about genetic testing and related procedures. Clinical geneticists are trained to diagnose patients who may have been unable to find a medical reason for their condition and may provide an end to the diagnostic odyssey many patients travel through before their genetic diagnosis.[6]

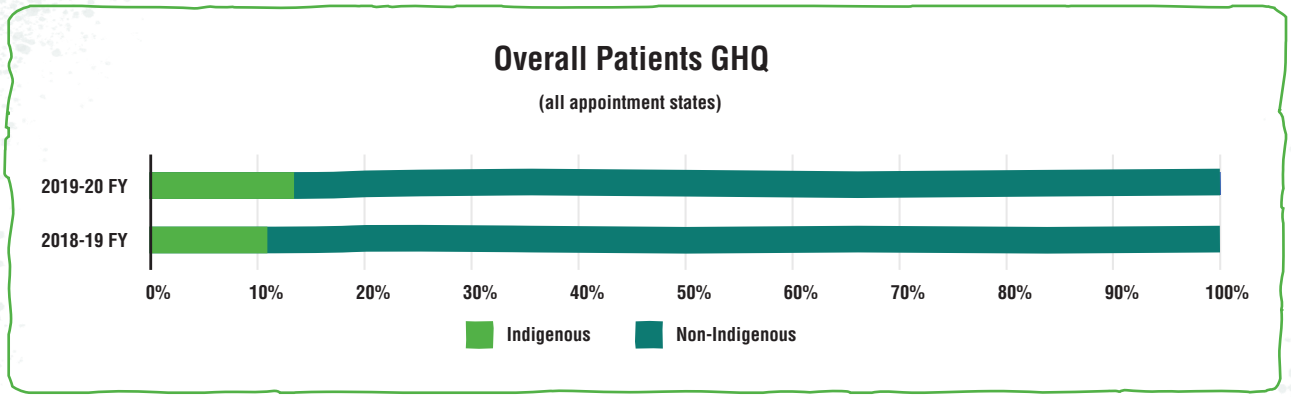
A genetic counsellor is an allied health professional who provides genetic counselling to patients. They undertake interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. They promote informed choices in view of risk assessment, family goals, ethical and religious values. Genetic counsellors also provide support to encourage the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. Genetic counselling is a communication process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial, and reproductive implications of the genetic contribution to specific health conditions.[7]

Both clinical geneticists and genetic counsellors provide education and information about the natural history of the condition, inheritance pattern, testing, management, prevention, support resources and current research. Both clinical geneticists and genetic counsellors work across the four areas described above.

Consumer Service Statistics

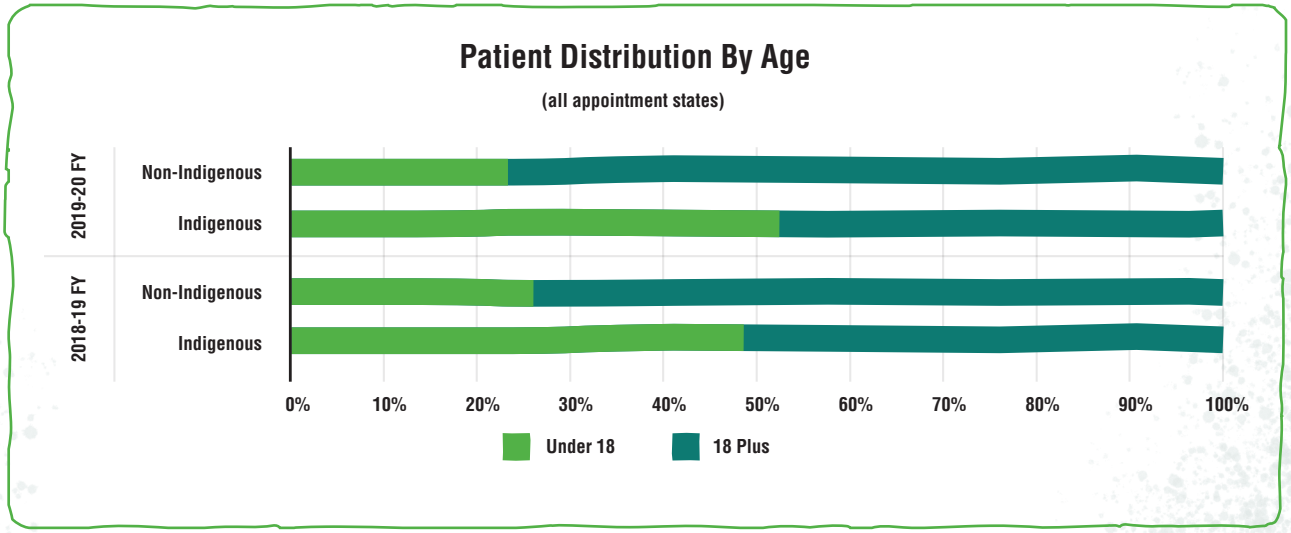
De-identified aggregate data for the period of 2018-2020, shows that the number of Aboriginal and Torres Strait Islander patients booked for GHQ appointments is representative. (Figure 2).

Figure 2 – Overall Patients GHQ



However, there is a greater proportion of booked appointments are for Indigenous patients under 18-years-old compared with the general population (Figure 3).

Figure 3 – Patient Distribution by Age



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ii. Integrated HealthCare

"'Integrated care' is a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health delivery systems."[8]

Integrated care is important when considering the needs of patients with complex health needs, supporting people to realise coordinated care through effective and shared responsibility for care planning between services. Integrated healthcare is realised through collaboration between services and across six domains:[9]

- functional (admin/back-office support functions)
- organisational (relationships between healthcare settings)
- professional (relationships in, within and between services)
- service or clinical (coordination and care across a single process)
- normative (shared mission and values)
- systemic (alignment of policies and incentives).

Integrated care breaks down disparities by reducing stigma, providing better coordinated care, and reducing and preventing heath disparities experienced by First Nations peoples internationally. It must be noted that integration of local beliefs and practices is also necessary.[10]

iii. Aboriginal and Torres Strait Islander Community Control and Primary Health

The Queensland Aboriginal and Islander Health Council (QAIHC) is the peak body for the 29 Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs) in Queensland, two Regional Bodies, 14 Associate Members and one Affiliate Member. Together, they form the ATSICCHO Sector.[11] ATSICCHOs embody a holistic view of health, *"not just the physical wellbeing of an individual but the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their potential and bring about the total wellbeing of their community." It is a whole of life view and includes the cyclical concept of life-death-life"*[12] ATSICCHOs are 'a primary health care service initiated and operated by the local community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it, through a locally elected Board of Management'.[13]

ATSICCHOs deliver holistic care that is 'patient or family centred', at no cost to the patient, at a single location. In delivering comprehensive primary health care, ATSICCHOs provide treatment, prevention and early intervention, rehabilitation, and recovery services. The family's engagement is critical to supporting individual health advancement. Flexibility in providing services is necessary, including home visits, hospital visits, outreach, telehealth, and family care plans. Clinical services are designed to address prevention, treatment and management of chronic disease, the major contributor to the health gap in Australia. Aboriginal and Torres Strait Islander Health Workers or Aboriginal and Torres Strait Islander Health Practitioners (ATSIHWPs), nurses, and general practitioners, supported by specialists and allied health professionals, work together as a team to address the complex health concerns faced by patients. ATSIHWPs lead coordination of the services for the patient/family and care is shared between a team of clinicians promoting a shared care arrangement.

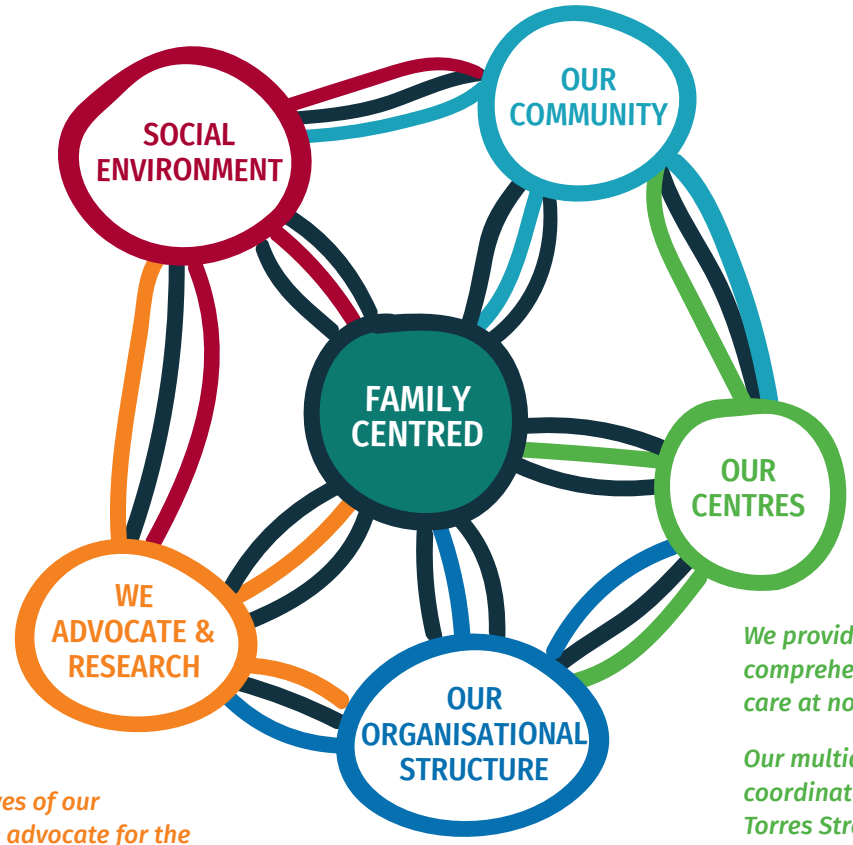
ATSICCHOs integrate social and emotional wellbeing treatment and support into patient care plans. They understand that mental, spiritual, and holistic wellbeing is vital to good physical health. ATSICCHOs commonly integrate public health knowledge, education, and practice into everyday service delivery. Aboriginal and Torres Strait Islander people (generally Health Workers) deliver health promotion activities, attracting community participation and ensuring that approaches are culturally appropriate and regionally relevant. Additionally, community health promotion events are held regularly at ATSICCHOs, either delivered by trained staff or supported by external agencies.

ATSICCHOs understand the position and role they play in supporting their communities to live better lives. The ATSICCHOs approach has evolved out of an inherited responsibility to provide flexible and responsive services that are tailored to the needs of local Aboriginal and Torres Strait Islander communities. ATSICCHOs provide a suite of services to ensure their community receive the services they need. In line with their holistic health approach ATSICCHOs support the social, emotional, physical, and cultural wellbeing of Aboriginal and Torres Strait Islander peoples, families, and communities.[14]

Figure 4: QAIHC – ATSICCHO Model of Care

We understand that our people are only as strong as their communities. We acknowledge the impact of social determinants on our health and work with community to advance other social domains.

Our service delivery is guided by our cultural values. We provide a care environment that is culturally safe and engage our communities and consult on matters that affect them. We value capacity building of individuals, families and communities.



We provide a single-point of comprehensive primary health care at no cost to our patients.

Our multidisciplinary team is coordinated by Aboriginal and Torres Strait Islander Health Workers. Our patients have access to a range of clinicians on site.

As representatives of our communities we advocate for the health needs of our families.

We practice data sovereignty and build partnerships with key stakeholders to enhance our evidence base.

We have a highly skilled Aboriginal and Torres Strait Islander workforce committed to Continuous Quality Improvement.

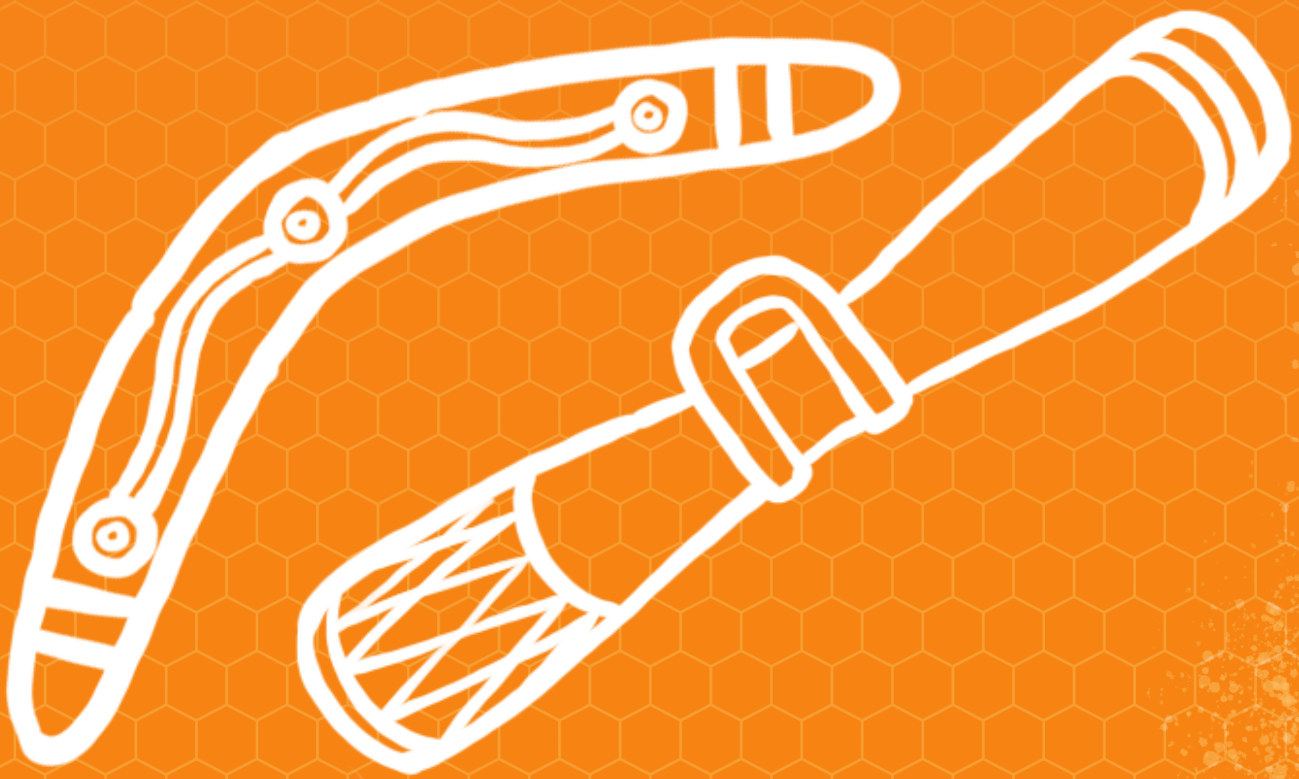
We provide assistance to our patients to reduce practical barriers and actively practice clinical excellence.

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PRINCIPLE 1: HEALTH PROMOTION

"Health promotion is the process of enabling people to increase control over and improve their health."[15] An appreciation and commitment to health promotion benefits patients, their families, their community, ATSICCHOs and public health providers. Within the principled space of health promotion, three core themes were identified:

1. community engagement
2. public awareness
3. language, media and medium.



Theme 1.1: Community Engagement

Community engagement and listening, as well as recognising community voices are key to building relationships. Genetic health can be a key enabler to support Aboriginal and Torres Strait Islander peoples to have a positive impact on their health and wellbeing.

Key messages arising from consultations:

- people are keen to learn about genetics
- priority health concerns raised include:
  - endocrine disorders, including diabetes
  - mental health disorders, illness and suicide
  - cardiovascular disease
  - cancer.

Potential Barriers:

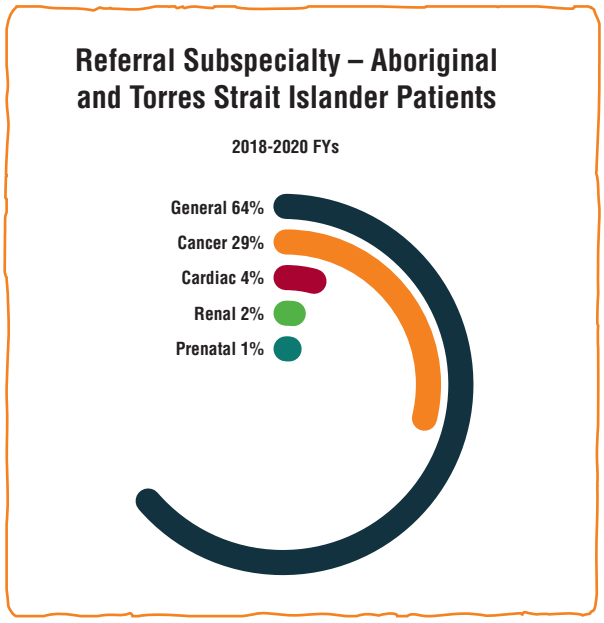
- Community raised concerns about non-health agency and government having access to health information.
- Patients may, for a variety of reasons, prefer not to go to hospitals.
- Family relationships and ties with health care providers may complicate a person's decision to access care at a hospital or health service.
- Genetic health may not be well understood or a priority for some patients.

Strategies and recommendations:

1. Sharing case studies and using dreamtime stories are a way to promote, inform, educate and engage.
2. GHQ to develop and sustain relationships with communities of Queensland based on trust, evidencing a commitment to community, reciprocal and respectful engagement, and supporting and contributing to community led conversations about genetic health with a view to promote genetic health as a topic of interest.
3. GHQ to attend and contribute to community meetings at the discretion and by invitation of ATSICCHOs and their communities.
4. GHQ staff to connect with Elders, sharing information about the service and the positive impacts it can have.

De-identified aggregate data for 2018-2020, describes genetic subspecialty referrals of Aboriginal and Torres Strait Islander patients (Figure 5). While overall, the number of Aboriginal and Torres Strait Islander patient appointments booked is representative of Queenslanders who identify as Aboriginal and Torres Strait Islander (4%),[16] there is a skew towards classification of "General" as most referrals were for paediatric patients.

Figure 5 – Referral Subspecialty – Aboriginal and Torres Strait Islander Patients



*General relates to a large group of conditions that do not fit into other clear subspecialties. Examples of conditions classified as General are: Marfan syndrome, Huntington's disease, muscular dystrophy, cystic fibrosis, and fragile X syndrome.

Theme 1.2: Public Awareness

Currently there is limited awareness and knowledge in the community about GHQ. The public is generally unaware of what they do, and that GHQ are part of the public hospital and health system (HHS) and provide free genetic counselling and free clinically indicated genetic testing.

Strategies and recommendations:

1. Link genetic conversations with other health services e.g. mums and bubs services.
2. Share case studies of positive experience for Aboriginal and Torres Strait Islander peoples accessing GHQ – make genetic health relatable.
3. Translate GHQ messages and information into dream time stories.
4. Standardised messaging across the board for all patients.
5. Be visible in the community.
6. Community breakfasts, BBQs and celebrations with local people, patients, consumers, and families.
7. Share positive patient stories.
8. QAIHC to advocate for better access to genetic health information through updates via their social media platforms, website and articles in the QAIHC Sector Leader Magazine, which has a readership of 5,000 people across Queensland.
9. QAIHC to lead translation of GHQ messages into locally acceptable medium and media and to empower community members to make informed health decisions.
10. GHQ stalls at community events.
11. Contribute to and be involved Aboriginal and Torres Strait Islander celebrations (e.g. NAIDOC, Coming of the Light and Reconciliation Week).

Theme 1.3: Language, Media & Medium

Using a variety of media outlets and mediums is key to successful health promotion that aids people and respects their preferences, language needs and right to access meaningful health messaging.

Key messages arising from consultations:

- Community members use a variety of social media platforms to keep informed about health.
- Staff were positive about the importance of displaying health literacy and promotional materials about genetic testing in ATSICCHOs waiting rooms.
- Use of plain language on information sheets is vital.
- Using dreamtime stories and culturally accepted language and narrative, rather than language designed from the perspective of a biomedical healthcare system is important.
- Using the term 'blood' is relatable; the story of DNA and genetics being in our blood is relatable.

"Blood is not an unusual term. It's a very familiar term and knowing that your blood is your story and sacred"

– Cairns Workshop

Strategies and recommendations:

1. Use leaflets and videos designed specifically by and for Aboriginal and Torres Strait Islander people.
2. Viable health promotion media should incorporate use of both digital and print medium.
3. Develop and display videos on closed circuit TVs in waiting rooms (e.g. Tonic Media).[17]
4. Use Aboriginal and Torres Strait Islander Newspapers, Television and Community Radio (e.g. NITV™[18], BBM 98.7fm[19], Koori Mail[20]).

5. Use screen savers on ATSICCHO staff computers.
6. Develop clinical genetics and family history modules for deployment of touch screen media outlets (e.g. Hitnet).[21]
7. Develop, distribute, and display posters and brochures.
8. Promote access to, knowledge of and the importance of incorporating local language.
9. Local Aboriginal and Torres Strait Islander Health Workers or Aboriginal and Torres Strait Islander Health Practitioners can support patients and GHQ by advising on access to interpreting services.
10. Written information should be available in both English and Creole for people in the Torres Strait.
11. GHQ to provide information to support platform pages of:
    a) ATSICCHOs
    b) Regional Areas
    c) Queensland Health
    d) QAIHC
    e) HHSs
    f) Primary Health Networks (PHN).

"Creole is the preferred language, particularly for starting conversations"

– Torres Strait Islands Workshop

PRINCIPLE 2: COORDINATED HEALTHCARE

An integrated approach to health service provision encourages collaboration between services and supports coordination and a quality health service experience for the patient. Clarifying the specific staff learning needs and responsibilities throughout the patient journey, we identify key points where integration of services is needed. Within the principled space of Coordinated Healthcare, five core themes were identified:

1. interagency collaboration
2. shared Learning
3. communication
4. referral
5. appointments.



Theme 2.1: Interagency Collaboration

Collaboration between GHQ and ATSICCHOs is integral to a smooth referral pathway which supports patients and the community to access a quality health service experience.

> *"You need every organisation's help to progress… once you start making connections half the job's done."*
>
> – Mount Isa Workshop

Key messages arising from consultations:

- GHQ is part of Metro North HHS and employ outreach staff in various locations across Queensland (Cairns, Townsville, Rockhampton, Bundaberg, Mackay, Sunshine Coast, Toowoomba and Gold Coast). All communication must be coordinated via Brisbane, Metro North (Appendix 3).
- Staff of GHQ to consider how to communicate knowledge of the significance and implications of a test for Aboriginal and Torres Strait Islander patients and their families.

Potential Barriers:

- A full day GHQ clinic requires six appointments to be viable. Further, to be a host for a GHQ clinic, ATSICCHOs need to be able to provide GHQ personnel with access to Queensland Health IT systems.

Strategies and recommendations:

1. Streamline communication between ATSICCHOs and GHQ for continuity of service to patients.
2. Be aware and respect the roles and responsibilities of each organisation and its staff.
3. Have open lines of communication.
4. Non-Indigenous staff should want to learn about Aboriginal and Torres Strait Islander culture.
5. Understand how to make a referral and GHQ's process of assessing and responding to that referral.

Theme 2.2: Shared Learning

Staff members of GHQ and ATSICCHOs commit to engaging in a shared learning experience that acknowledges and supports professional development; as well as availing the opportunity to contribute to learning for their partner organisation.

Strategies and recommendations:

For GHQ staff:

1. Understand how ATSICCHOs work, who is involved, what the service offers and holistic healthcare.
2. Cultural awareness – recognition and understanding the significance of Aboriginal and Torres Strait Islander cultures and the influence of political, social, historical and economic circumstances.
3. Cultural safety – recognition and understanding implications and application of Aboriginal and Torres Strait Islander cultural safety for clinical practice.
   - QAIHC's definition of cultural safety is *"Cultural safety is about respecting the rights, values, beliefs and expectations of Aboriginal and Torres Strait Islander peoples while providing services that meet their need. Cultural safety is distinguished from cultural 'awareness' as it relates to embedding culturally sound practices into all elements of delivery, rather than merely recognising that cultural differences exist."*[22]
4. Participate in orientation to local culture and cultural protocol for individual communities.
5. Understand the difference, significance and implication of women's and men's business.
6. Awareness of, and commitment to seek advice about the use of appropriate language to engage and support a patient accessing quality health care.
7. Awareness and education about the importance of seeking guidance regarding cultural protocol when enquiring about family history (e.g. kinship and adoption practice in the Torres Strait).
8. Awareness and education about the importance of seeking guidance regarding cultural protocol when enquiring about deceased and estranged family.

For ATSICCHO staff:

1. What GHQ does, who is involved, and how it works.
2. How to identify a patient to be referred to GHQ.
3. Awareness of Clinical Prioritisation Criteria (CPC) at GHQ.
4. Understanding what can be billed and coded.
5. What is the difference between a genetic counsellor and a clinical geneticist?
6. Education about genomics, genetic testing, and precision medicine.
7. Understand how to explain genetic testing to a patient and their family.
8. Make patients and relatives aware that GHQ may ask about deceased and unwell family members.
9. Collection, storage, use and repatriation of biological material for genetic testing.

For both GHQ and ATSICCHO staff:

1. Education and updates for both ATSICCHOs and GHQ (e.g. newsletters).
2. Regular in-services (i.e. face to face and virtual).

Theme 2.3: Communication

The public health system is based upon a biomedical approach to health, which in turn has implications for how health practitioners communicate about testing, diagnosis, treatment and health care.

Key messages arising from consultations:

- Patient consent must be obtained for GHQ to forward a copy of the patient appointment letter to the referring GP.
- ATSIHWPs can support engagement and break down clinical jargon.
- GHQ send clinic letters to the referring doctor throughout a patient's care and at the conclusion of its service provision. Most patients discharged from GHQ do not require genetic follow up, additionally GHQ will advise if any on-referring to other specialists is required and suggest if other family members should be referred.
- GHQ clinic letters in most cases will not require urgent follow up by the referrer but will be sent no later than 2 weeks post dictation following an investigation and/or episode of service by GHQ.

Potential Barriers:

- There are several reasons why patients may not receive correspondence or respond to contact:
  - Patients attending family and community business away from their usual residence for extended periods of time.
  - Official looking correspondence with the Queensland Government logo (in particular, envelopes), can be off putting for recipients and deter people from opening letters.
  - Patients changing phone numbers.
  - Insufficient phone credit to reply to missed calls or text messages.
  - Not answering unknown numbers.

Strategies and recommendations:

1. Patients supported to familiarise themselves with the environment where they are receiving care.
2. Call patients before their appointment, introduce yourself and explain the reason you are contacting them.
3. Subject to patient consent, appointment letters and correspondence will be sent to the patient, their referring doctor and the ATSIHWP of the ATSICCHO. By sending appointment correspondence to ATSICCHOs, ATSIHWPs can follow up with patients to inform and assist with their appointment, including transport.
4. GHQ to consult with the referring doctor and ATSIHWP for the ATSICCHOs and at each stage of the patients' accessing and receiving a service from GHQ.
5. Identify a specific staff member within GHQ for ATSICCHO staff to contact with respect to supporting improved patient care and service coordination.
6. Identify a specific staff member within each ATSICCHO for GHQ staff to contact with respect to supporting improved patient care and service coordination.

7. Monthly GHQ appointment list of ATSICCHO patients to be sent to coordinating ATSICCHO personnel.

8. With patient consent, ATSIHWPs to provide input and advice to GHQ about the patient, their preferences, circumstance, and health history before their initial appointment.

9. Ensure all patients are asked if they would like an ATSIHWP with them at their appointments.

10. Clinic letters, results summaries, and requests for additional appointments from GHQ to be forwarded to ATSICCHO referring doctor as soon as is practicable.

11. ATSIHWP will arrange to contact the patient to go through outcomes of the referral, test results and implications (i.e. family implications or additional tests).

Theme 2.4: Referral

Having a clear process of how to refer and what to include will improve ease and experience for both staff and patients.

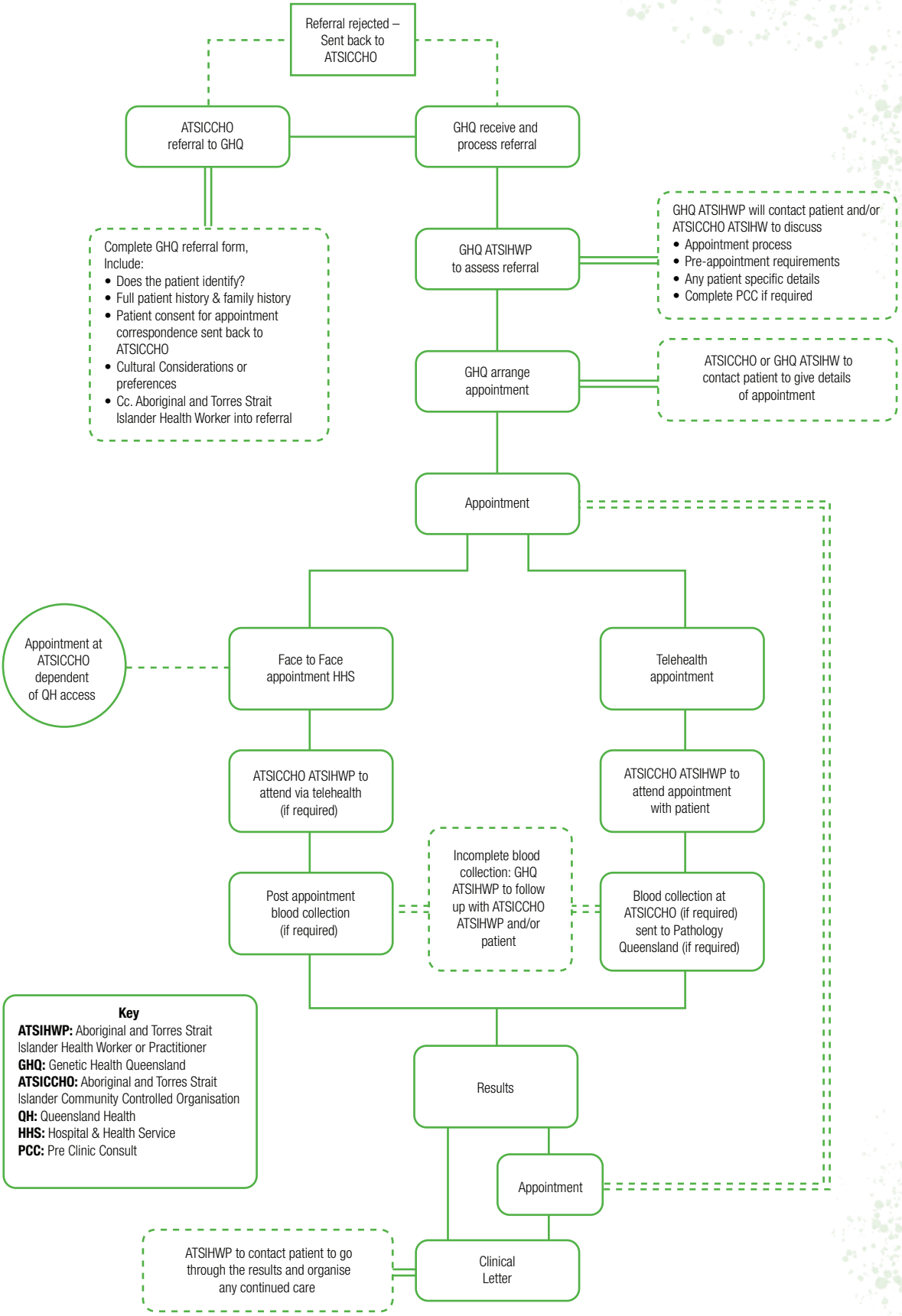
Key messages arising from consultations:

- Medicare Benefits Scheme (MBS) Item 715 Aboriginal and Torres Strait Islander Peoples Health Assessment[23] is a preventative health care check conducted in primary health, specifically for Aboriginal and Torres Strait Islander patients. Completion of the 715, is the perfect opportunity to discuss genetic health concerns and potential referral to GHQ.
- There needs to be a simple step-by-step pathway to highlight who is principally responsible for coordinating care of the patient.

Strategies and recommendations:

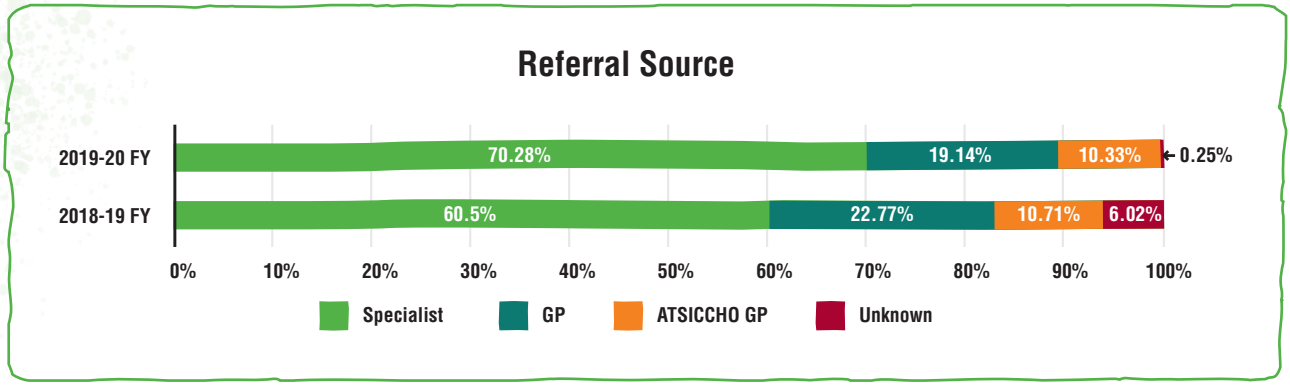
1. Add alerts/reminders to discuss genetic health during MBS Item 715 health assessment.
2. The referral to GHQ must include:
   a) relevant clinical information to address referral guidelines.
   b) whether the patient identifies as Aboriginal and/or Torres Strait Islander
   c) full patient and family history
   d) any cultural considerations or preferences of the patient
   e) patient consent to allow GHQ correspondence to be sent to ATSICCHO
   f) ATSICCHO and ATSIHWPs as a cc'd recipient of the referral.
3. Once GHQ has received the referral:
   a) Post triage and standard administration process, Aboriginal and Torres Strait Islander patients are transferred to GHQ ATSIHWPs.
   b) GHQ ATSIHWP to contact ATSICCHO ATSIHWP and/or patient to discuss how GHQ works and what to expect.
   c) GHQ ATSIHWP to conduct any Pre-Clinic Consult (PCC) via telehealth at the ATSICCHO rather than via the phone and if possible/preferred by the patient. This means that any consent to collect info can be organised at the time so there is minimal delay to appointment.
   d) If a patient declines their referral to the ATSICCHO the GHQ ATSIHWP will be the main point of contact to assist the patient with their referral.
4. On the rare occasion that a referral is not accepted by GHQ, GHQ will advise the referring doctor of their decision and explain why the referral has not been accepted.

Referral Pathway Flow chart



De-identified data for 2018-2020, describes where referrals source for Aboriginal and Torres Strait Islander peoples (Figure 6). There are consistently higher referral rates from specialists and the bulk of these referrals are for patients under 18 years old.

Figure 6 – Referral Source



*Referral source could not be identified from available data

Figure 7 - MBS 715 Aboriginal and Torres Strait Islander Peoples Health Assessment data in Queensland

MBS 715 Aboriginal and Torres Strait Islander Peoples Health Assessment data in Queensland

According to Medicare data and compared with other states and territories of Australia, Queensland consistently complete the highest number of MBS 715 assessments.[24]

July 2020-March 2021 – 59,290 assessments
2019-20 FY – 80,448 assessments
2018-19 FY – 87,190 assessments

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Theme 2.5: Appointments

There are multiple steps to ensure that an appointment is successful for patients. Services working together can connect with the patient to ensure a smooth transition from the referral to attending the appointment.

Key messages arising from consultations:

- Transport was a major concern and consideration for patients, especially for people traveling from regional and remote areas.
- Most ATSICCHOs offer transport for patients from their local area to be able to attend appointments at their clinic.
- The HHS provides financial assistance for eligible patients to access specialist medical services not available locally; this scheme is referred to as the Patient Travel Subsidy Scheme (PTSS).[25] Aboriginal and Torres Strait Islander patients can request that a support person (referred to under the scheme as an escort) travel with them for cultural reasons, however this is at the discretion of the patient's local HHS. Referring clinicians must explicitly state this as the reason that an escort is required. Patients can also request an escort if there is a language barrier. An escort is always provided to patients under 18 years of age, regardless of family situation at the destination. While the scheme provides financial assistance, it is not intended to cover all out-of-pocket costs associated with accessing specialist medical services. For more information please refer to: **https://www.health.qld.gov.au/__data/assets/pdf_file/0033/848706/qh-hsdgdl-050-2.pdf**
- GHQ appointments are with genetic counsellors and clinical geneticists and are only confirmed in consultation with the patient.
- Rates of failure to attend for Indigenous patients compared with non-Indigenous patients, is consistently higher (over double the rate for the past two financial years).
- Telehealth services allow clinicians to connect with patients remotely in real time, via video conferencing services.
- GHQ appointments can be arranged as a telehealth appointment and patients are able to request that they dial in from home.
- Due to the nature of some genetic conditions, telehealth is not always a suitable appointment type. In these instances, face-to-face appointments can be organised at GHQ outreach clinics in the HHS locations (Appendix 3).
- Following a GHQ appointment, if clinically indicated, and with patient consent to proceed to testing, blood can be collected at an approved specimen and blood collection service (some ATSICCHOs are accredited). This eliminates the need for a patient to go to the hospital for blood collection. All samples must be sent to Queensland Pathology for processing and analysis. In the instance of a face-to-face appointment at the hospital, bloods can be collected at the HHS.

Potential Barriers:

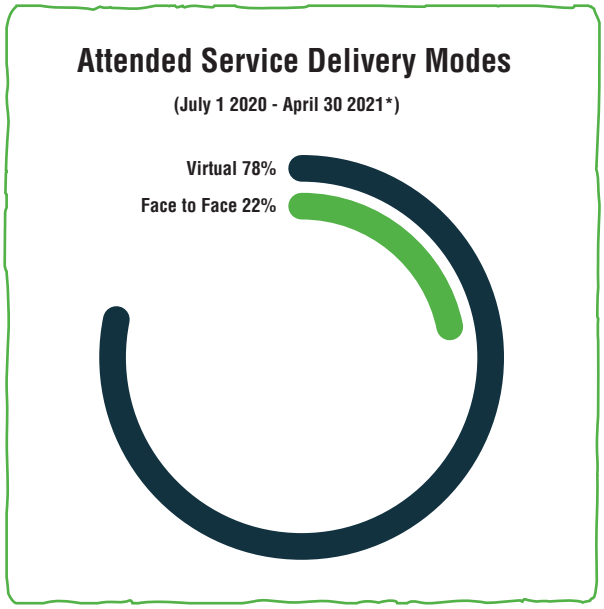
- Availability and access to transport to attend face-to-face appointments.
- Patients not having enough money to pay for transport to get to appointments.
- Limited public transport options.
- Not receiving appointment letters and/or correspondence.
- Limited access to high-speed internet and equipment/software to support telehealth services.[26]

Strategies and recommendations:

1. Identify a support person at GHQ to liaise at HHS level and advocate for patient to access PTSS.
2. If a patient is having an appointment with GHQ (via telehealth or face-to-face), consider holding the appointment at the ATSICCHO. There are numerous possible benefits:
   a) If available, transport can be easily organised.
   b) An ATSIHWP can be present and clarify queries and concerns.
   c) ATSICCHOs can bill Medicare for:
      - MBS item number 10983, recipient end attendance able to be billed if an ATSIHWP (min cert III) or practice nurse participates in the consultation.[27]
      - There are also MBS items if a medical officer or midwife participate in the consultation.[28]
   d) Queensland Health's Telehealth Portal can be accessed externally using a web link and portal technical support is available to ATSICCHOs.
   e) Where it is the preference of the patient to have their appointment via telehealth at their home, offer the option for an ATSIHWP to attend in person (where available and a part of the services available and provided by the respective ATSICCHO).
3. For patients traveling from out of area for a face-to-face appointment, there may not be the option for the ATSICCHO ATSIHWP from their hometown to be present. In these circumstances, the ATSIHWP can link in via telehealth. There is also the option to connect with the local ATSICCHO and/or HHS ATSIHWP.
4. Where the ATSICCHO offer an approved blood collection service and with patient consent, bloods can be collected. Any incomplete pathology requests can be followed up by an ATSIHWP, such that GHQ gain an appreciation as to why the patient has not had bloods collected. If the patient needs any assistance this can be arranged.
5. Greater understanding from GHQ about the reasons why Aboriginal and Torres Strait Islander patients may fail to attend appointments.
6. Greater appreciation and understanding from patients and referring agents about fail to attend (FTA) rules.
7. Continuous engagement with patient before and after their appointment, develop a relationship and trust with the patient.

De-identified data for 2020-2021, describes the attended delivery mode of appointments for Aboriginal and Torres Strait Islander patients (Figure 8). Having included only attended appointment data, for the period from July 2020 to April 2021, a majority of Aboriginal and Torres Strait Islander patients were seen virtually. Patients being seen close to home can help to remove barriers to access and ensures the patients who are seen virtually have the surrounding support.

Figure 8 – Attended Service Delivery Modes

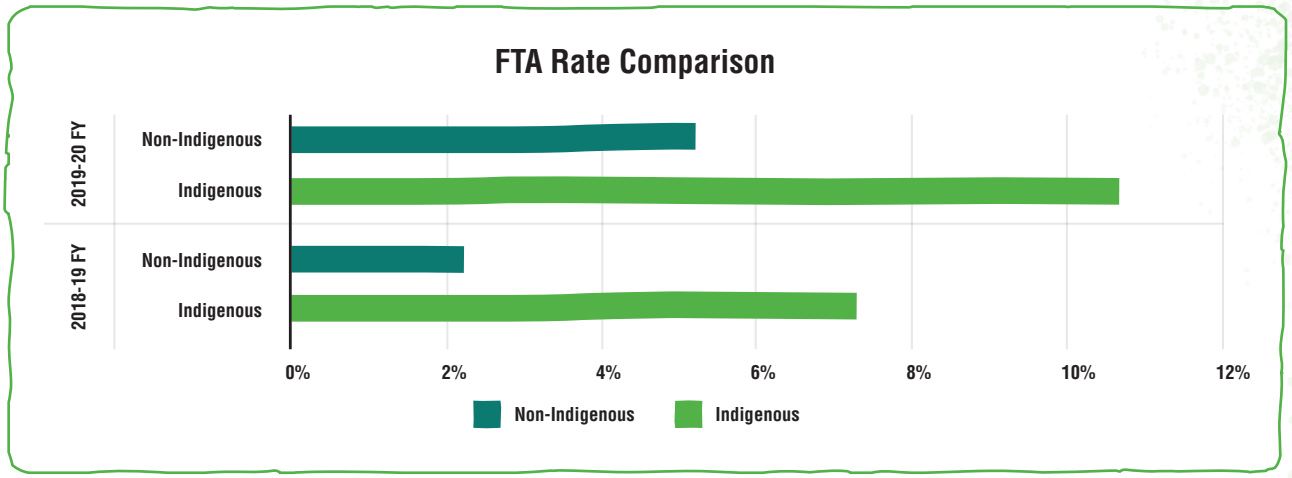


*Due to a change in policy with how GHQ conducts virtual care post COVID-19, it would not be accurate to use older data.

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De-identified data for 2018-2020, describes the FTA rate of Indigenous compared with non-Indigenous persons (Figure 9). Aboriginal and Torres Strait Islander patients are more than twice as likely to FTA as non-Indigenous population. This shows us that there are barriers to accessing and attending GHQ appointments that need to be addressed.

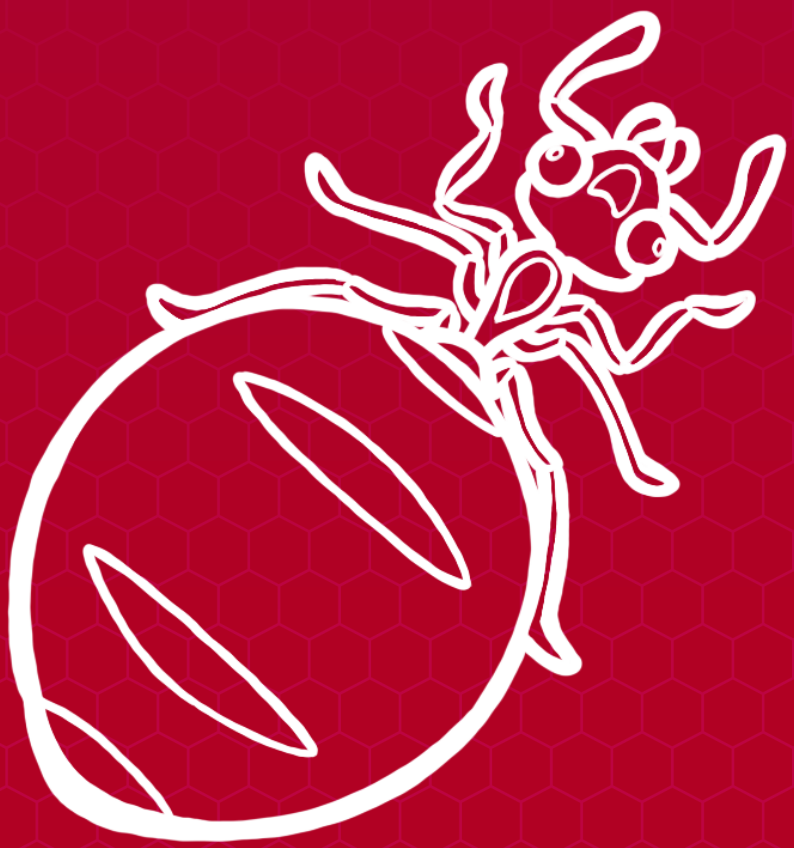
Figure 9 – Failed to Attend (FTA) Rate Comparison



PRINCIPLE 3: WORKFORCE

Workforce plays a critical role in the provision of quality healthcare, building relationships in the community and improving access for patients. A strong workforce aids the strength and structure of integrated care between services, as well as develops relationships and trust with community, people, families and patients. In the principled space of workforce, four core themes were identified:

1. GHQ
2. ATSICCHOs
3. leadership and genetic champions
4. training.



Theme 3.1: GHQ

Building trust is especially important for GHQ, as building trust with Aboriginal and Torres Strait Islander peoples will increase the likelihood of patients feeling safe and secure in their experience of accessing the service.

Key messages arising from consultations:

- It is important for non-Indigenous staff working with Aboriginal and Torres Strait Islanders patients to understand and appreciate cultural differences.
- Non-Indigenous staff should have knowledge of local culture, specifically relating to genetic healthcare, for example:
  - Spoken dialect, be sensitive to cultural taboos including sorry business, women's and men's business and traditional terminology such as referring to people as 'Aunty' or 'Uncle'.
  - Genetic variation between the diverse and various Aboriginal and Torres Strait Islander peoples within Queensland.
  - Adoption and kinship, the notion of family is more than being genetically related.

Strategies and recommendations:

1. GHQ to employ an Aboriginal and Torres Strait Islander person like an ATSIHWP. This person will be the main point of contact for ATSICCHOs.
2. GHQ must be aware that there will be different ATSICCHO personnel throughout the pathway who can support and provide advice about matters relating to women's and men's business.

"When you go out to the community, you've got to be culturally appropriate to that community."

– Bundaberg Workshop

Theme 3.2: ATSICCHOs

All staff must understand their role in supporting patient referral and a quality health service experience. This will support decision making that acknowledges and considers affordability, accountability, trust and diminishes the potential for political and personal factors to complicate health service delivery.

Key messages arising from consultations:

- The GP plays an integral role in the patent referral from the ATSICCHO by:
  - treating the whole family
  - understanding patient and family history
  - beginning the genetic conversations at the patient's health assessment (715).
- Only doctors can refer a patient to GHQ.
- Throughout the workshop consultations, the importance of an ATSIHWP was identified as a key factor influencing, supporting and coordinating patient care.

"Our health workers are an integral part of our service because they're out there with their clients, with the community, talking about the specialist, why they should see them. So, I know our doctors always refer back to health workers."

– Townsville Workshop

Strategies and recommendations:

1. Ideally, all members of the ATSICCHO workforce (including locum/fly-in) should have a Cert IV Aboriginal and Torres Strait Islander Primary health care qualification.
2. ATSICCHOs to ensure locum doctors are upskilled within the genetic space and integration between the services, this can be done by:
   a) quick reference guides developed by ATSICCHOs
   b) local community training
   c) online modules and face-to-face training courses (developed in partnership with GHQ).

3. Support professional development of ATSIHWP to increase knowledge of genetic health. An ATSIHWP will:
   a) promote the importance and benefits of genetic health
   b) support the GP with cultural considerations for the patient referral
   c) develop and foster relationships with GHQ
   d) support the patient and GP with PTSS (if applicable). As well as having ability to seek support from GHQ if required
   e) assist both the patient and GHQ clinician at appointments, with regards to local culture, language, lore and protocol
   f) support patient attendance at GHQ appointment.

Theme 3.3: Leadership and Genetic Champions

Leaders across the public hospital and health service sector, ATSICCHO service sector, academia, policy, research and the community, acknowledge the value, importance, significance and potential for genetic health to benefit Aboriginal and Torres Strait Islander peoples.[29] Genetic health must be part of any strategic plan that purports to reduce the burden of disease and support resolution of long-term health concerns of patients, their family and the community.

Key messages arising from consultations:

- For integration and success, GHQ and ATSICCHOs must serve as champions and leaders in the provision of equitable and accessible quality genetic healthcare. Champions will advocate for GHQ and ATSICCHO and the importance of genetic health.
- Leaders should ensure information is disseminated to their workforce, with clear communication and transparency.

Strategies and recommendations:

1. Identify a genetic champion within ATSICCHOs, to serve as a single point of contact and coordination in the acquisition, development and dissemination of genetic health knowledge.
2. QAIHC to support ATSICCHOs to identify and resource genetic champions.
3. Make available a key contact within GHQ to support ATSICCHOs in navigating genetic health and referral pathways.
4. Establish clear leadership in genetic health within each sector:
   - ATSICCHOs
   - QAIHC
   - HHS
   - GHQ.

Theme 3.4: Training

Training is the linchpin that will build positive clinical partnership between ATSICCHOs and GHQ. There must be successful, evidence-based training for both services if there is to be long term improvement for Aboriginal and Torres Strait Islander people's healthcare.

Key messages arising from consultations:

- Successful training methods were identified throughout consultations:
  - animations and/or visual aids
  - training tailored to specific workforce
  - full day training broken into different areas
  - informal mentoring
  - safe environments where participants do not feel threatened
  - education specialists involved in training packages
  - a mixture of hands on training and online training
  - ongoing training and education where necessary
  - training to be recognised.

Potential Barriers:

- Lack of appropriate resources.

Strategies and recommendations:

1. ATSICCHO staff will receive training around genetic health and testing.
2. GHQ staff will receive training around cultural capability and safety.
3. Training requirements were highlighted for specific roles and their training:
   a) ATSIHWP would prefer more face-to-face, hands-on learning. This gives opportunities for participants to ask questions which would be lacking in online education.
   b) Education for GPs to claim CPD points will encourage doctors to engage. This can include courses, conferences and online training which will be useful for GPs.

RECOMMENDATIONS

An overview of the key recommendations throughout the document.

Health Promotion

1. GHQ to develop and sustain relationships with communities.
2. Link genetic conversations with other health services.
3. Case studies of positive experience of Aboriginal and Torres Strait Islander people accessing GHQ.
4. Translate GHQ messages and information into dream time stories.
5. Standardised messaging across the board for all patients.
6. QAIHC to advocate and lead translation for better access to genetic health.
7. Viable health promotion media should incorporate use of both digital and print medium.
8. Local Aboriginal and Torres Strait Islander Health Workers or Aboriginal and Torres Strait Islander Health Practitioners able to support patients by speaking and advising on access to local language and interpreting services.
9. Written information should be available in both English and Creole for people in the Torres Strait.

Coordinated Healthcare

1. Streamline communication between ATSICCHOs & GHQ for continuity of service to patients.
2. Be aware and respect the roles and responsibilities of each organisation and its staff.
3. Understand how to make a referral and GHQ's process of assessing and responding to that referral.
4. GHQ & ATSICCHOs to utilise defined resources, knowledge and services of each other's service and commitment to improved patient care.
5. Ongoing education for both ATSICCHOs and GHQ.
6. Subject to patient consent, appointment letters and correspondence will be sent to the patient, their referring doctor and the Aboriginal and Torres Strait Islander Health Worker or Aboriginal and Torres Strait Islander Health Practitioner of the ATSICCHO.
7. Identify a specific staff member within GHQ for ATSICCHO staff to contact with respect to supporting improved patient access, care and service coordination.
8. Aboriginal and Torres Strait Islander Health Worker or Aboriginal and Torres Strait Islander Health Practitioners to play a key role throughout each and every patient's journey.
9. Integrate discussing genetic health during MBS Item 715 health assessment.
10. Identify a support person at GHQ to liaise at a HHS level and advocate for patient to access PTSS.
11. Consider holding GHQ appointment (via telehealth or face to face) at the ATSICCHO if viable.
12. Continuous engagement with patient before and after their appointment, develop a relationship and trust with the patient.

Workforce Development

1. GHQ to employ an Aboriginal and Torres Strait Islander person, this person will be the main contact for the ATSICCHOs.
2. GHQ must be aware that there are appropriate staff members throughout the pathway that can cover both women's and men's business.
3. ATSICCHOs to ensure locum/fly in doctors are upskilled within the genetic space and integration between the services.
4. To develop Aboriginal and Torres Strait Islander Health Workers or Aboriginal and Torres Strait Islander Health Practitioners knowledge of genetic health to support a patient's journey.
5. Identify a genetic champion within the ATSICCHO, to be a single point of contact with additional knowledge in relations to genetic health.
6. ATSICCHO staff will receive training around genetic health and testing.
7. GHQ staff will receive training around cultural capability and safety.

APPENDICES

Appendix 1:

Methods

Through collaboration between QAIHC, GHQ and QIMR Berghofer, a series of workshops were facilitated in urban and regional locations across Queensland. Research was appropriately conducted[30] through consultations designed to confer, engage, and empower Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs), primary and public health service providers, community representatives and champions to describe a preferred integrated genetic healthcare model and referral pathway for improved access to genetic testing services of GHQ.

The process consisted of nine workshops held across Queensland. It was important that we captured different voices across the state. Workshops were held at ATSICCHOs in Toowoomba, Brisbane, Bundaberg, Rockhampton, Townsville, Cairns, Mount Isa, Napranum and Thursday Island. Between January and February 2021, 52 participants from ATSICCHOs, PHNs, HHSs, researchers and community members were involved in the workshops.

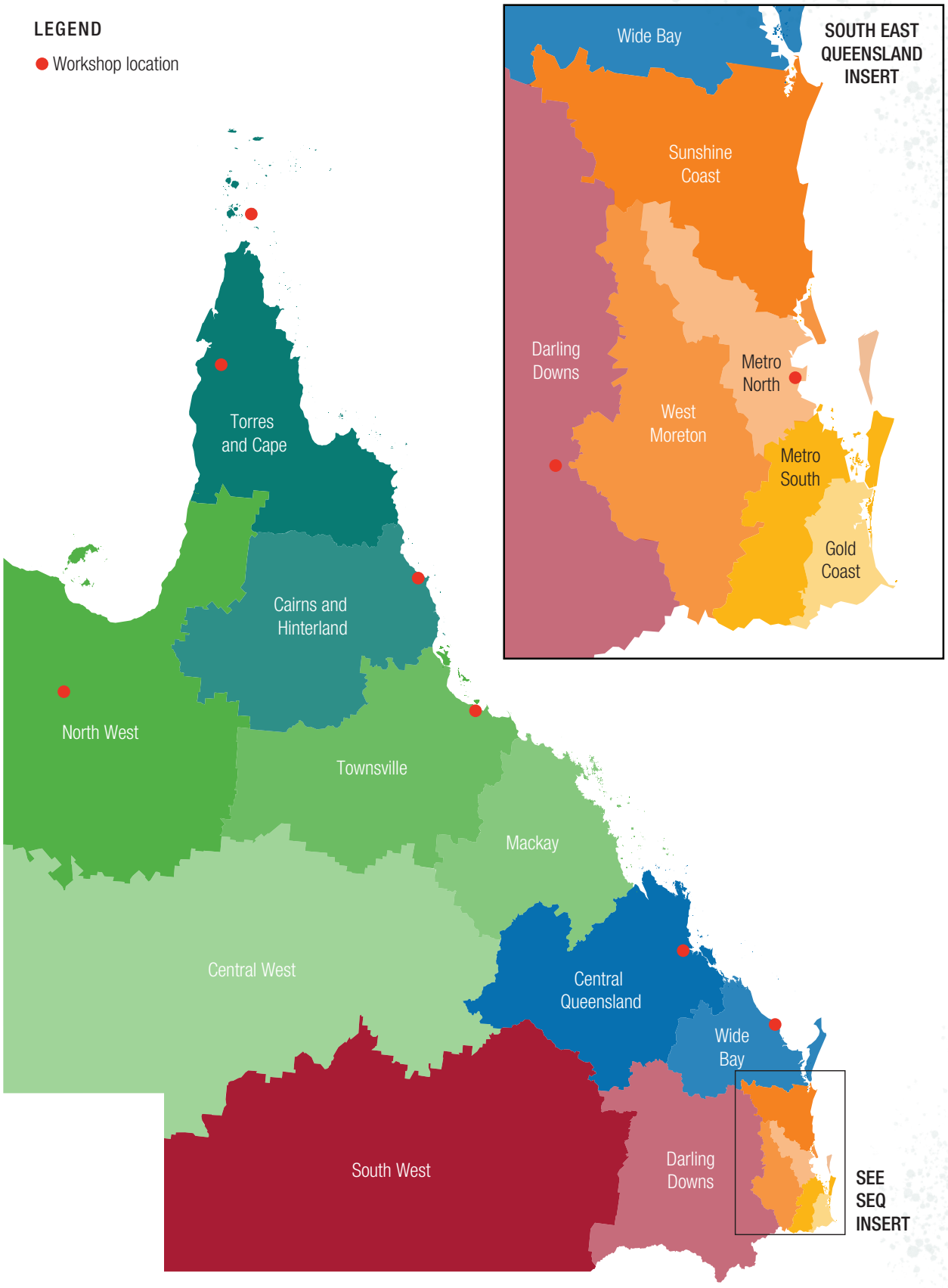
During the workshops, expert advice was sought from stakeholders to identify barriers and enablers of service utilisation for Aboriginal and Torres Strait Islander Queenslanders in the context of genetic testing and counselling. This included identifying and exploring topics of integrated service provision, workforce investment and the promotion of services accessed by the community. Topics stakeholders were asked to consider included:

- How can we learn more about genetic health?
- What do you think would be important for GHQ to know about ATSICCHOs?
- How do we ensure shared responsibility for continuity of care and that patients do not fall between the gaps?
- Is upskilling and training the existing workforce going to meet the needs of the Aboriginal and Torres Strait Islander patients to access genetic health care services? Are new staff with specialist skills required?
- What training needs do staff require to better support patient access to GHQ?
- What are the obvious barriers of services working together?
- How important is communication to integrated care? How frequently, what purpose and what form?

Post workshop and analysis, a draft version of the *Integrated Genetic Health Care: Improving Access for Aboriginal and Torres Strait Islander People to Clinical Genetics through Partnership and Primary Health Leadership* was produced electronically. Feedback was sought from and provided by participants involved directly in the workshops alongside contacting and consulting stakeholders who were unable to attend workshops. Consultation and feedback finalised penultimate versions of the document.

Limitations

Unfortunately, due to limitations imposed by COVID-19 restrictions and subject to time constraints, not all HHSs and not every ATSICCHO for Queensland was able to host/attend a workshop.


LEGEND
Workshop location
SOUTH EAST QUEENSLAND INSERT
Wide Bay
Sunshine Coast
Darling Downs
Metro North
West Moreton
Metro South
Gold Coast
Torres and Cape
Cairns and Hinterland
North West
Townsville
Mackay
Central West
Central Queensland
Wide Bay
South West
Darling Downs
SEE SEQ INSERT

Appendix 2

Abbreviations

Acronym	Definition
ATSIHWP	Aboriginal and Torres Strait Islander Health Worker or Aboriginal and Torres Strait Islander Health Practitioner
ATSICCHO	Aboriginal and Torres Strait Islander Community Controlled Health Organisation
CPC	Clinical Prioritisation Criteria
CPD	Continuing Professional Development
FTA	Failed to attend
FY	Financial Year
GHQ	Genetic Health Queensland
HHS	Hospital and Health Service
NITV	National Indigenous Television
MBS	Medicare Benefit Scheme
MBS 715	Aboriginal and Torres Strait Islander Health Check
MBS 10983	Telehealth—patient-end clinical support service by a practice nurse, Aboriginal and Torres Strait Islander Health Worker, Aboriginal and Torres Strait Islander Health Practitioner
PCC	Pre-Clinic Consult
PHN	Primary Health Network
PTSS	Patient Travel Subsidy Scheme
RBWH	Royal Brisbane and Women's Hospital
QAIHC	Queensland Aboriginal and Islander Health Council
QH	Queensland Health
QIMR Berghofer	Queensland Institute of Medical Research

Glossary

Clinical Genetics The application of genetic services and genomic testing in a health care setting.

Clinic Letters Correspondence of a clinical nature between health care professionals and/or patients.

Coming of the Light A holiday celebrated by Torres Strait Islanders on July 1st, recognising the adoption of Christianity throughout the Torres Strait Island communities.

Community As defined by Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018) (The Guidelines)[31] – page 25: "…is recognised as a complex notion incorporating cultural groups, geographic groups or groups sharing common interests. It may include a group or organisation and is also a term used to describe a shared view amongst Aboriginal and Torres Strait Islander Peoples."

De-identified The separation of data from a dataset, which could potentially make an individual identifiable or executed in a way that the identifiable data may be reconnected with the dataset.

Elder Someone who has gained recognition as a custodian of knowledge and lore, and who has permission to disclose knowledge and beliefs.

Genomic Testing We all have about 20,000 genes in our genomes. Our genes are made of DNA and contain the instructions for growth and development of the body. Until recently, doctors and scientists were only able to test one gene at a time. Genomic technology allows us to test many of our genes at once (genomic testing).

Identifiable A dataset containing data that can identify the individual.

Kinship The heart of Aboriginal and Torres Strait Islander culture. Kinship will look different across communities; it helps to determine a person's relationship to others and their responsibilities to people and Country.

NAIDOC NAIDOC Week celebrations are held across Australia each July to celebrate the history, culture and achievements of Aboriginal and Torres Strait Islander peoples.[32]

Reconciliation Week A chance for all Australians to learn shared histories, cultures and achievements, while exploring how each person can contribute to achieving reconciliation in Australia.

Regional & Remote Areas Categorised by the Australian Bureau of Statistics (ABS)[33] "…Remoteness Areas divide Australia into 5 classes of remoteness based on a measure of relative access to services."

Sorry Business An important time of mourning that involves a person, family and community attending responsibilities and obligations to pay respect to the deceased (e.g., attending funerals and life celebration events and ceremonies for the person who has passed).

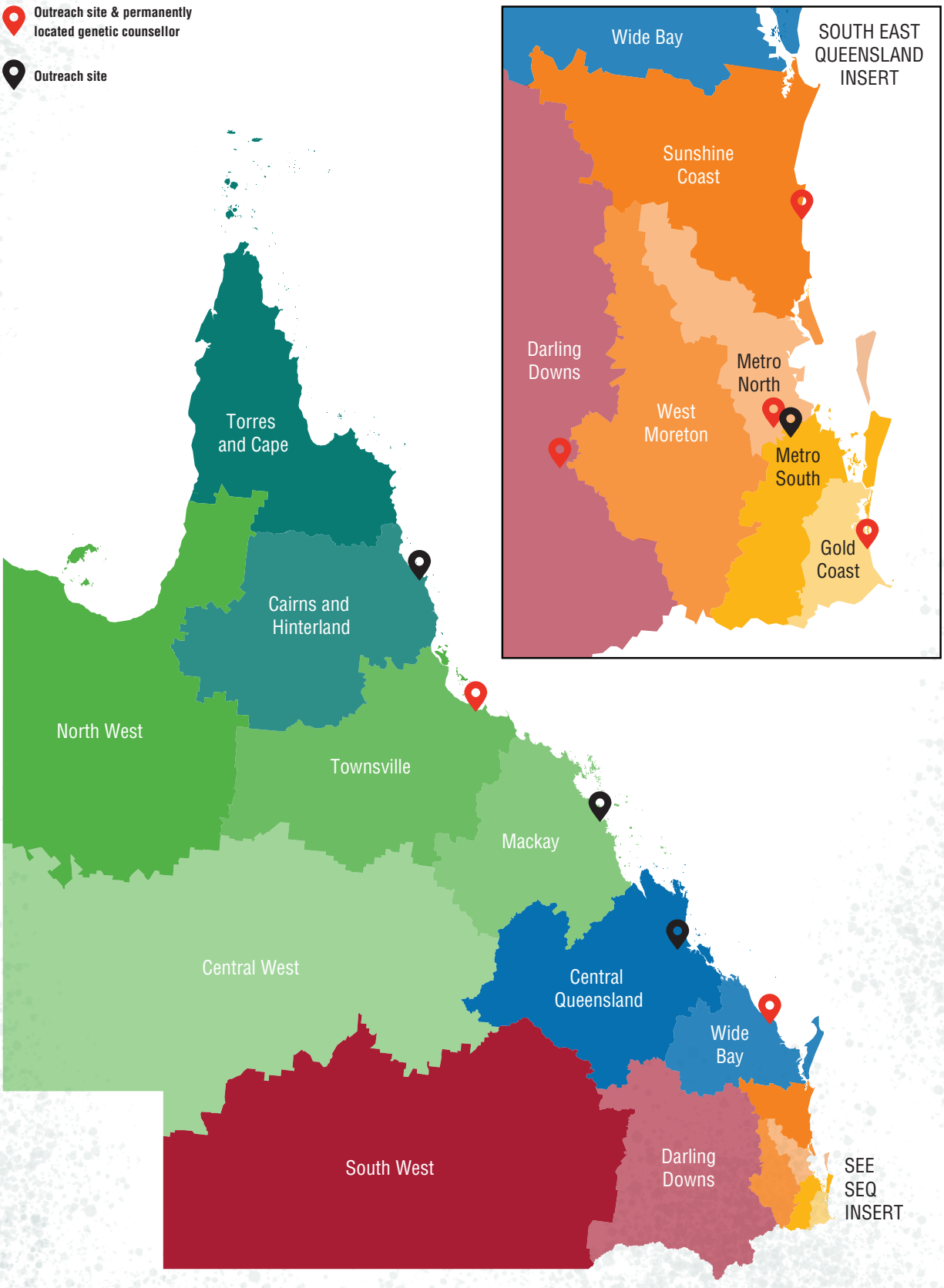
Telehealth As defined by Australian Government, Department of Health[34] It is about transmitting voice, data, images and information rather than moving care recipients, health professionals or educators. It encompasses diagnosis, treatment, preventive (educational) and curative aspects of healthcare services and typically involves care recipient(s), care providers or educators in the provision of these services directed to the care recipient.

Virtual Care (VC) Is defined as the absence of a physical presence between the clinician and the patient facilitated through information technology and communication modalities. In delivery terms, VC encompasses telephone, telehealth (videoconferencing platforms such as Telehealth Virtual Clinic, Telehealth Portal & Microsoft teams) and other alternative information and communication technologies, approved by Queensland Health for patient related consultations and care.

Women's and Men's Business Traditional, customs and practices performed by women or men only. In the modern context of health and the Community, when discussing topics considered women's or men's business there is usually a splitting of genders to discuss issues.

Appendix 3:

GHQ Clinic Locations



Appendix 4:

Data Statement

Aggregate patient appointment data from GHQ data has been de-identified. All appointment states and appointment types (excluding chart reviews) are used in the data to cover full patient journey unless listed as a caveat.

Figure 3
Collected data only provided for age at the time of data collection, data filters were modified to included patients who are now over 18 years old but were under 18 years old at the time of service.

Figure 5
"General" relates to a large group of conditions that do not fit into other clear subspecialties Examples of conditions classified as General are Marfan syndrome, Huntington's disease, muscular dystrophy, cystic fibrosis, fragile X syndrome.

Figure 6
Data adjusted to ensure duplicates removed (same patient with multiple occasions of service for same referral); "Unknown" not enough information in the data used to determine referrer.

Figure 7
Data sourced from the MBS Item Statistics Reports website.[24]

Figure 8
Data for current financial year to date used due to extensive changes to GHQ Virtual care policy, previous years data would be inaccurate to measure against in this instance. Checked out appointments only to show what modes are being attended.

Figure 9
Appointments in FTA state only, the same patient may FTA more than once so may be represented several times.

Data Storage, Safety & Privacy

GHQ is bound by strict laws to maintain patient confidentiality. It is an offence to provide or access patient personal and medical information except under limited circumstances as prescribed by legislation. Additionally, all patient data is stored securely in databases that meet Australian/international standards and guideline.

In the course of caring for a patient, information will be shared with other medical professionals involved in the patient's care including their referring doctor, other specialists caring for the patient or the patients usual GP. This information is shared to provide comprehensive and appropriate care to the patient however, if at a future time the patient no longer wants information shared with one of these parties, they need to advise GHQ.

The nature of genetics means that patient results may have an impact on other family members. With patient consent only, results may be released to another clinical genetics service to assist in the care of other family members to ensure correct and appropriate testing and advice. When this information is shared, all efforts are made to ensure patient identity is not disclosed to those family members. This consent can be withdrawn at any time by the patient by contacting GHQ directly or the RBWH Information Access Unit.[35]

Research is an important part of health care advancement. Patients may be asked to provide consent to share data for research into the same or a related condition in a way that may be linked back to them. The personal identifiers will be removed from the patient information or sample and replaced by a code. If there are findings from this research that have implications for the patient's clinical care, it may be possible to re-identify the patient, so that the results can be returned. However, participating in research does not guarantee direct patient benefit.[36] All researchers are bound by the law and ethical guidelines. This research will only happen for projects approved by a human research ethics committee. Declining to consent to research will not prevent the patient from accessing clinically appropriate healthcare with GHQ. Additionally, consent can be withdrawn at any time by contacting GHQ directly, RBWH Information Access Unit or the entity conducting the research if known.

Patients have the right to apply to access for information held in their medical records. To do this GHQ patients can make a Right to Information request to the RBWH information access unit. The patient will also need to provide proof of identity before the request is considered. This request process also applies to collected samples (tissue, blood) but there are additional requirements relating to management of samples due to their classification as Hazardous Biochemical Waste in law and need to be handled as such with special approvals. There is also a process to obtain other people's health records/samples (e.g. deceased relative), which follows a similar process but with additional requirements to ensure, the requester is an appropriate person to receive the information.

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