Statewide Genetic Health Queensland Service Plan

2017–2022

Queensland Government

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Acknowledgement

This statewide plan has been developed Metro North Hospital and Health Service in partnership with Genetic Health Queensland. Metro North Hospital and Health Service acknowledge the support received from staff across Genetic Health Queensland, Pathology Queensland, Department of Health, other Hospital and Health Services and Rare Voices consumer group to develop this Plan.

Introduction

Clinical genetics is evolving from a discipline primarily focused on the diagnosis and management of rare chromosome and single gene diseases, to an expanded role that is influencing care pathways and pharmaceuticals for precision medicine. Mainstream services are seeking greater integration and support from clinical geneticists in the diagnosis and management of multisystem disorders across a range of speciality areas. In turn, clinical genetics is reliant on research that evaluates genetic discoveries and impacts to patient care.

There is growing interest surrounding the potential and promise of genetics that is equally met with caution, given the complexity of unresolved issues such as the protection of genetic information. This rapidly changing service environment has implications for service planning and delivery.

Clinical genetics services are designed to diagnose and assist individuals and their families who are affected by or may be at risk of hereditary conditions or birth defects to make informed decisions about their healthcare. Services typically include genetic diagnosis, screening and testing, counselling, information, advocacy and support.

As with any clinical discipline that is changing, there is a need to assess the adequacy of current service arrangements to determine whether services are meeting the health needs of patients safely, equitably and ethically. Based on this assessment the way to evolve and change service design can be determined. In 2015 the Department of Health prepared the Genetic Health Queensland (GHQ) Report to support Queensland public clinical genetics to:

- be optimally positioned to respond to health service needs within an evolving clinical policy environment so that improved healthcare is accessible to Queenslanders
- develop service capability to respond to statewide public health service needs through optimal integration of services
- be effectively supported and enabled through adequate supply of workforce, appropriate support infrastructure and funding mechanisms.

The Report identified the following items for Metro North Hospital and Health Service (MNHHS) (as the host Hospital and Health Service for GHQ) to develop in partnership with GHQ:

- a comprehensive service profile including the nature of genetic health services, service delivery arrangements, target population and clinical governance arrangements
- links with mainstream and specialist genetic workforce to promote and facilitate education, information and standards of genetic care
- mechanisms to advise on service availability for primary health care providers, other medical specialities and public health professionals
- service delivery approaches to maximise use of available resources and reduce the need for patient travel.

This Statewide Genetic Health Queensland Health Service Plan (the Plan) has been developed in response to the GHQ Report and the actions identified above. The Plan also considers the growing interest and commitment at a state level to the principles of excellence to support innovation, research and evidence-based care. This Plan provides further analysis of the Queensland public genetic health service system including pathology testing and provides service directions and actions to support GHQ to respond to health service needs within an evolving clinical policy environment. All actions will be progressed over the next five years, any actions requiring additional resources will be subject to normal budgetary processes.

Genetic health services in Queensland

2.1 The role of Genetic Health Queensland

GHQ provides a highly specialised service delivered by a small team of specially trained clinicians whom play an important role in diagnosing and managing genetic disorders that can affect all ages and body systems, from evaluating, screening patients at risk for inherited disease, to the treatment of inherited disorders such as cystic fibrosis. Highly trained clinicians assess and diagnose the complex and often sensitive ethical issues that arise through genetic testing. GHQ is currently delivered as a statewide service, hosted by MNHHS, due to the small numbers of clinical geneticists practising in Queensland (6.4 FTE as at June 2017) and the specialist nature of the service.

2.2 Current service delivery network

In Queensland, GHQ is responsible for delivering statewide public genetic health services for adults and children. GHQ provides diagnosis, counselling and management advice to individuals and their families who have, or at risk of having a genetic or inherited condition. Services are delivered by a multidisciplinary team comprised of clinical geneticists and genetic counsellors who provide diagnosis of genetic conditions and offer counselling to assist in decision making for individuals and their families, and dedicated administrative support staff. Services are delivered using a range of modalities including face to face, telehealth and telephone to ensure services are provided as close to home as possible.

Genetic services are enabled by laboratory genetic testing services provided predominantly by Pathology Queensland (PQ). PQ provides pathology services to all Queensland Health public hospitals through a single integrated statewide network spanning across 34 laboratories. Depending on organisational capacity and capability, PQ either undertakes genetic testing internally or engages external providers for a fee.

Public genetics services in Queensland are delivered by GHQ via a statewide hub and spoke service model. As at September 2016 the GHQ service model included:

- the 'hub' or central office of GHQ located at the Herston Campus which is host to several general adult clinics. The hub is also responsible for management and allocation of GHQs statewide funding allocation for genetic testing
- clinical and administrative input to three sub-specialty clinics at Royal Brisbane and Women's Hospital (RBWH) in cardiac genetics, renal genetics and prenatal counselling
- paediatric clinics undertaken by clinical geneticists at the Lady Cilento Children's Hospital (LCCH)
- visiting clinical geneticist services at the Gold Coast, Toowoomba, Nambour, Bundaberg, Rockhampton, Mackay, Townsville and Cairns Hospitals
- genetic counsellors providing local clinics at Bundaberg, Herston, Gold Coast, Lady Cilento Children's, Nambour, Toowoomba and Townsville Hospitals
- genetic counsellors providing telehealth clinics to Cairns, Mackay and Rockhampton Hospitals
- clinical geneticist and counsellor telehealth/ telephone services are provided as required statewide.

2.3 Current service activity

The majority of GHQ services are delivered in an outpatient setting. Services are delivered by a variety of modalities including face to face, telehealth or telephone by clinical geneticists, genetic counsellors or specialists either individually or as part of a joint clinic arrangement. Key statistics are described below:

- between 2010-11 and 2014-15, there was a 16 per cent increase in the number of referrals to GHQ
- between 2012-13 and 2014-15, the number of patients waiting for an outpatient appointment increased by 19 per cent
- there has been a six per cent increase in GHQ occasions of service between 2013-14 and 2014-15
- the use of face to face consultation has been declining with a slight increase in the use of telehealth and telephone occasions of service between 2013-14 to July-December 2015
- in 2014-15, 81 per cent of GHQ services were provided to adults, 19 per cent of GHQ services were provided to children (0-14 years of age)
- based on HHS population information and current utilisation of GHQ services, resident access to GHQ services is lowest for Torres and Cape HHS and highest for Sunshine Coast HHS in 2014-15
- the volume of genetic tests ordered by GHQ grew by 47 per cent (857 genetic testing referrals to PQ) between 2012-13 and 2014-15
- the top three tests ordered by GHQ in 2014-15 were associated with breast or ovarian cancers and contributed to 30 per cent (793) of all tests ordered .

2.4 Overview of current model of care

Specialist GHQ model

GHQ receives referrals for adults and children for a diverse array of genetic disorders such as a personal or family history of known or suspected genetic conditions e.g. birth defects, rare diseases and cancer. Referrals are assessed by a clinical geneticist at the hub site using eligibility criteria and categorised for treatment according to the severity of the patient's condition (Table 1 and Table 2).

Once GHQ accepts a referral and prioritises treatment, the patient will be seen by a clinical geneticist, genetic counsellor or both. GHQ provides clinical diagnosis, clinical risk assessment, diagnostic and/or predictive genetic testing and education to patients with or at risk of a genetic disease via clinical geneticists and genetic counselling services. In high complexity cases, such as rare conditions, the clinical geneticist will coordinate care across specialities to ensure continuity of care and expert geneticist advice across disciplines. GHQ serves as a central resource for information about genetic disorders for patients and health professionals.

Over the past few years, a number of informal service models have evolved between GHQ and selective clinical services including joint clinics with mainstream clinical services that combine expertise to improve patient diagnosis and management of genetic disorders. A description of the model and current application is provided below.

Table 1: GHQ referral criteria

Paediatrics	• babies and children with medical and developmental issues with a suspected genetic or chromosomal cause or at risk of a genetic condition • children at risk of a genetic condition
Adults	• adults with known or suspected hereditary disease or congenital abnormality • individuals with a family history of hereditary disease or congenital abnormality • individuals at risk of a genetic condition
Prenatal	• pregnant women with a personal or family history of disease • couples who meet criteria of increased risk of having children with a genetic condition
Cancer	• children and adult patients with a personal or family history of cancer that is suspected to have a heritable basis
Cardiac	• individuals with a personal or family history of a cardiac condition that is suspected to have a heritable basis
Renal	• individuals with a personal or family history of renal condition that is suspected to have a heritable basis

Table 2: GHQ referral criteria

Category 1 - appointment within 30 days	• condition is urgent and may require more complex care if assessment is delayed
Category 2 - appointment within 90 days	• condition likely to require predictive genetic testing or pre-conceptual counselling
Category 3 - appointment within 365 days	• condition unlikely to deteriorate quickly

Joint clinics

Joint clinics offer a multidisciplinary approach to managing complex medical conditions and are delivered by expertise in different areas of care delivery. An important feature of this model is the tailored combination of differential diagnosis discussion, disease information provision and genetic counselling that offers a multidisciplinary approach to improved patient diagnosis through translation of genetic science advances to clinical application. There are several joint clinics in operation between GHQ and other mainstream specialist areas that combine specialist and clinical geneticist expertise, genetic counsellors, ancillary clinical and diagnostic services. In these models, GHQ is responsible for running these clinics, with ongoing management provided by the mainstream specialist.

This service model is currently operating for:

- renal services at the RBWH, LCCH and telehealth to regional hospitals
- cardiac services at the RBWH, LCCH, Townsville, Cairns and telehealth to regional hospitals
- endocrine services (tumour-predisposing conditions) at the Princess Alexandra Hospital (PAH).

Mainstream services

The growing momentum for diagnosis and genetic testing across many other Queensland mainstream clinical services to support diagnosis and management is currently approached in two ways:

1. Under guidance: testing is undertaken in the presence of defined standards; and
2. Ad-hoc: genetic testing is undertaken in the absence of defined standards.

There is limited oversight or review of the clinical appropriateness and utility of these tests and no referral pathways where mutations are identified in individuals. However, there has been a surge in the number of genetic tests being requested by mainstream clinical services across HHSs in recent years.

2.5 Current workforce arrangements

GHQ services are provided by a range of professionals including clinical geneticists, genetic counsellors and laboratory geneticists. GHQ Full Time Equivalent (FTE) workforce in June 2017 included:

- 6.4 FTE clinical geneticists
- 15.67 FTE genetic counsellors
- 10.84 FTE administration.

Table 3 displays the locations and workforce information at which GHQ provides services. The 'hub' service is based at the MNHHS Herston Campus and spoke services are located as far as Wide Bay HHS. Clinical geneticists are employed by the hub site (Herston Campus) and provide services statewide. Genetic counsellors are employed by the hub site and some are located in spoke HHSs across Queensland.

Table 3: Overview of GHQ current service, Full Time Equivalent (FTE) and headcount by HHS location

GHQ workforce	Total FTE	Total Headcount	HHS Locations
Clinical Geneticists	6.4	5.0	MNHHS (hub at Herston Campus provide outreach services across Queensland)
Genetic Counsellors	15.67	18.0	• Children's Health Queensland (LCCH) • Darling Downs • Gold Coast • MNHHS (Herston Campus) • Sunshine Coast • Townsville • Wide Bay
Administration	10.84	13.0	• Darling Downs • Gold Coast • MNHHS (Herston Campus) • Sunshine Coast • Townsville* • Wide Bay

Service challenges

The role of genetics in clinical care is evolving. Although somewhat controversial, rapid advancements in genetic testing technologies are changing the way healthcare is provided and have the potential to improve health, prevent disease and improve treatment options particularly for at risk populations. In 2016 a greater number of genetic tests are available to clinicians compared to 10 years ago—offering new methods for improved diagnosis and treatment for a range of genetic disorders.

For GHQ, these changes have had notable impact on service delivery, evident by the increasing number of referrals and patients waiting times for genetic outpatient services in Queensland despite an increase in the supply of services. These trends are also impacting PQ, where there is sustained growth in the volume of genetic tests requested by GHQ and other specialities.

These changes have posed a number of service delivery challenges not only for GHQ as the provider of genetic services for Queensland but also for the broader public health system given the complexities surrounding this rapidly evolving area. The key issues are summarised below.

The policy environment

- The limited national direction regarding the role of genetics in health will be addressed in the National Health Genomics Policy Framework 2017-2020 which is pending release by the Australian Government will provide guidance to the statewide service direction and address policy issues and challenges to current practice including the handling of incidental findings, the protection of genetic information, and discrimination based on future health risk revealed by genetic testing
- There is currently no framework to provide a consistent, national and strategic view to integrating genomics into the Australian health system and identify policy issues and challenges. In 2016, The Australian Health Ministers' Advisory Council established the National Genomics Policy Framework Advisory Group to develop a whole-of-governments, systems-focussed National Genomics Policy Framework for stakeholder engagement
- Limited statewide service direction has challenged GHQ's ability to respond to technology advancements, new models of care and increasing service demand. GHQ services have evolved over time in response to the service environment rather than a planned approach to population and service needs.

Genetic testing and the Medicare Benefits Schedule (MBS)

- Genetic counsellor sessions are not eligible for Medicare billing unless part of joint clinics with clinical geneticists restricting the adoption of innovative models of care
- Few genetic tests receive Government MBS benefit payment, despite being clinically indicated compared to other countries such as the United Kingdom
- Service demand is controlled, in part, by current significant costs of most genetic tests and small number of genetic tests eligible for Medicare rebate.

Increasing demand in a fiscally constrained service environment

- Increasing number of patients presenting to GHQ with multi-complex genetic disorders is impacting on clinical geneticist caseload. This is the case particularly for paediatric patients.

Community expectations

- Community expectations regarding genetic testing and GHQ services are increasing. Increasingly consumers expect health services to inform, empower and enable them to make timely and appropriate decision regarding care.

Number of patients waiting

- Increasing numbers of patients waiting for specialist genetic outpatient services across Queensland
- Long wait clinics include cardiac clinic at RBWH, general clinics at Cairns and Bundaberg Hospitals.

Equitable access to services

- Access to genetic services is variable across Queensland with people who live in rural and remote areas of Queensland having poorest access. HHS with poor access per 100,000 population include Torres and Cape, North West and South West HHSs
- Limited referrals to genetic services for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse persons.

Patient health literacy

- There is limited patient/family knowledge and understanding of the role of genetics in supporting health, diagnosis and managing disease
- There is limited education tailored to patients and their families to support patients to understand the genetic services available, their benefits and the potential outcomes.

GHQ service awareness

- Referrers are not clear on the GHQ services that are available, where and how frequently they are provided.
- Patients and family knowledge and understanding of services provided by GHQ prior to being seen by GHQ are limited or incorrect
- Patients and families unsure of where to access service and health information
- Wait times for services are not clear
- HHSs that do not have a local genetic counsellor have limited awareness of GHQ services
- Transparency of referral triage and waitlist management processes concern HHS spoke sites.

GHQ Operating model

- Complex internal administration and governance arrangements between GHQ and the RBWH have resulted in limited understanding and awareness of GHQ services and demands
- Spoke HHSs perceive GHQ approach to service provision for outreach clinics as unplanned and ad hoc
- No formal education program from GHQ to HHS clinicians regarding role and function of GHQ or opportunities to develop and implement joint or mainstream clinics
- Informal approach to connectivity between HHS spoke sites with genetic counsellor to advance local staff and patient education and training
- Due to lack of service level agreements with spoke HHSs, GHQs relationship with spoke HHSs is challenged resulting in poor sharing of resources to support outreach clinics
- Limited and capped funding for GHQ to support genetic testing across the State.

KinTrak data system

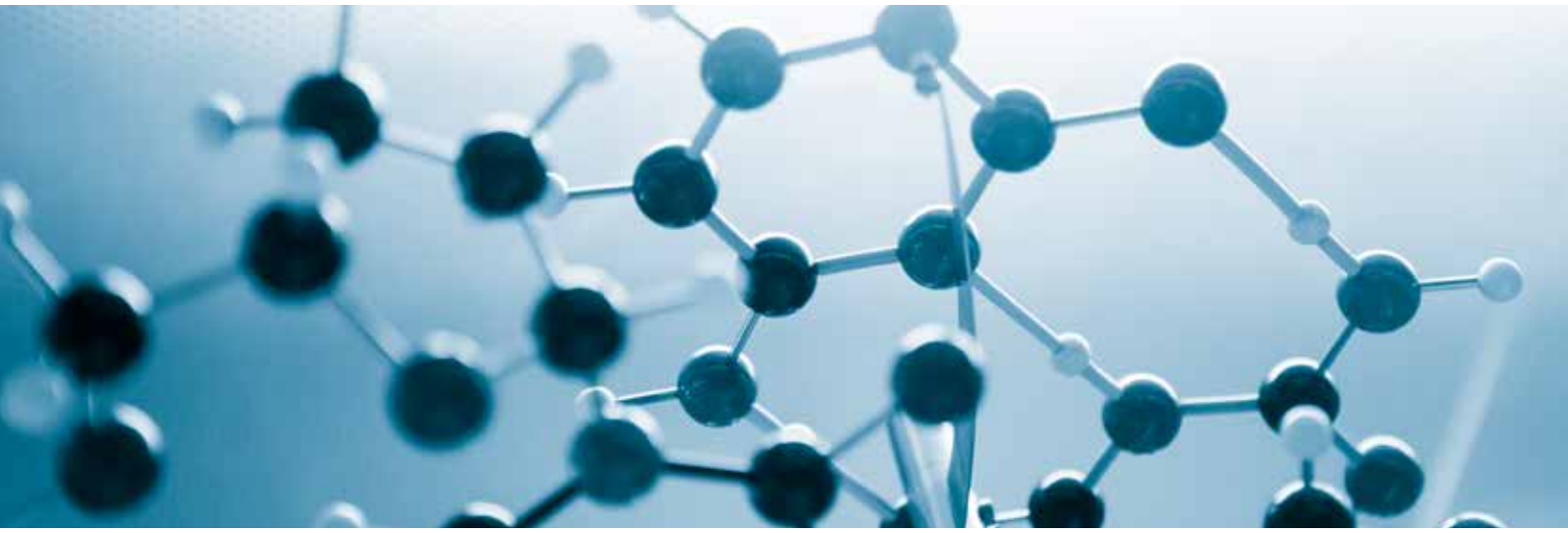
- KinTrak data system does not easily integrate with other clinical information systems including Hospital Based Corporate Information System (HBCIS)
- Referrers are unable to plan multidisciplinary clinics or reviews or coordinate appointments.

GHQ Workforce

- There are 62 qualified clinical geneticists working nationally of which 6.4 FTE work in Queensland (as at June 2017). Despite a further 20 in advanced trainee positions nationally, the demand for clinical genetic services exceeds the current small and highly specialised workforce available
- Recruitment to vacant clinical geneticist and genetic counsellor positions challenged due to highly skilled and specialised workforce
- No genetic counsellor presence in northern Queensland
- Based on the workforce benchmarks of the Human Genetics Society of Australasia GHQ have workforce shortages: across clinical geneticists, genetic counsellors and administration. The clinical geneticist's workforce is significantly lower than the benchmark
- Limited administrative support results in genetic counsellors and medical staff completing role and functions of administrative staff
- The current clinical workload of GHQ staff has hindered research capacity and ability to form linkages with research organisations.

Pathology Queensland Genetic testing issues

- Limited criteria and guidelines are available to support clinicians to select the most appropriate genetic test when diagnosing or ruling out disorders of genetic origin
- No statewide criteria to assess the cost utility/cost effectiveness of genetic tests
- Poor transparency of pricing for genetic pathology tests
- Limited awareness of waiting times for pathology testing/reports and lack of communication about these wait times to referrers and patients
- There is variation in turnaround timeframes for reports when benchmarking PQ with other laboratories
- PQ processes and systems do not support monitoring of genetic testing activity that is referred to other laboratories resulting in lost tests and duplicate requests
- Discrepancy in billing arrangements are being investigated by PQ
- There is minimal guidance to support clinicians in the appropriate selection of genetic tests
- Capacity and capability to support rapidly advancing tests are limited
- Less than one per cent of all PQ tests are related to genetic conditions.



Future service system

Advancements in genomic technologies will offer new ways to prevent, diagnose, treat and manage a range of genetic based diseases. In Queensland, there is growing interest and commitment to explore the potential of these advancements. The State is committed to supporting Queenslanders maintain and improve their health and wellbeing into the future, that is, deliver evidence-based health care, supported by innovation, research and the application of best practice to improve health outcomes. Genetics is a rapidly evolving field and provides an opportunity to realise this vision.

This Plan assumes the policy environment at a national and state level will develop and evolve over the next five years to keep pace with genetic and genomic sequencing technology advancements. The future genetic service system in Queensland will be capable of delivering evolving genetic services safely, ethically and equitably. Consumers are key partners in this process, recognising that genetics gives rise to specific ethical, legal and social issues. Transparent communication will assist to balance consumer expectations and provide appropriate service delivery.

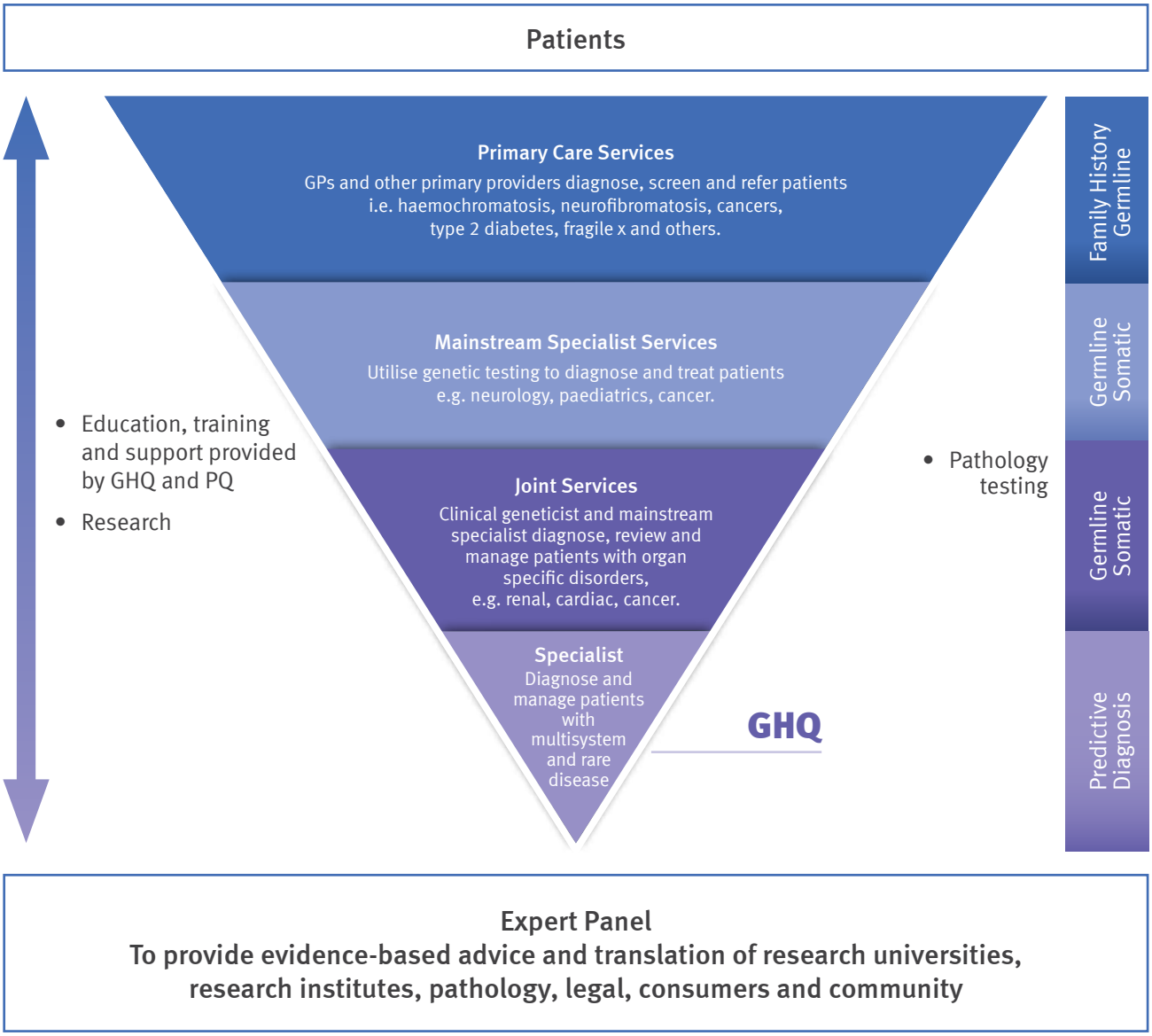
The future service system recognises the challenges in delivering genetic services sustainably and equitably across our dispersed State. GHQ will provide Queenslanders with equitable access to specialist genetic services via a networked service model, enhancing capacity, increasing telehealth and exploring new workforce models to meet demand, particularly in remote areas e.g. northern Queensland. The GHQ clinical geneticists workforce will be centralised at key locations, given the limited highly specialised workforce, with greater focus on expanding specialist services to target spoke sites, through new service delivery models, where there is currently limited access to GHQ clinics and where there is high need (as indicated by demand and long waits). Over time GHQ workforce capacity will grow to align with workforce benchmarks and statewide service need.

The role of GHQ will evolve, maintaining its focus on the delivery of specialist level services in the diagnosis and management of patients that present with multi-system or rare disease, but also, enhance and introduce joint and mainstream service models to deliver services sustainably. GHQ will also improve support and work in partnership with primary care providers including general practitioners to identify patients and families who would benefit from being referred to GHQ, to support clinical management of genetic conditions and to communicate genetic information.

To ensure Queensland is positioned to lead potential future advancements relating to clinical genetics and to enable timely transition of research into clinical service delivery, the establishment of an expert panel should be considered. The expert panel will not have a governance role, rather it will provide strategic direction to policy, ethical and social issues and will evaluate how genomic discoveries might impact patient care. This group could be comprised of clinical geneticists, mainstream service staff with interests in genetics, pathology, research institutes, universities and other relevant organisations statewide.

The attributes of the preferred service model are presented below. The tiered approach of the model recognises the presence and importance of genetics across multiple clinical disciplines in the diagnosis and management of patients, and evolving role of GHQ with greater emphasis on education, training, support and research. This model will ensure efficiencies of scale for highly specialised services whilst introducing a networked and coordinated approach to growing mainstream and joint services close to where people live.

Figure 2: Genetics preferred service model



Service Directions

This Plan provides service directions, each with its own set of objectives and actions to guide statewide service development. Actions have been grouped into two groups—those actions that should be implemented as a priority and those that can be achieved within the next five years. It is important to recognise that GHQ operate within a health service system with competing health needs and finite resources and that allocation of new resources required to progress the actions will be subject to normal budget processes.

5.1 Service Direction 1 – Queensland will have a clear policy positon to support advancements in genetic medicine

Queensland will continue to strengthen its involvement in national and state forums regarding clinical genetics, recognising the need to balance the potential and promise of genetic based discoveries with policy that supports sensible decisions regarding the use of genetic information.

GHQ will be supported by effective governance arrangements at MNHHS as the host site. Clear standards for service provision including clinical governance arrangements, alignment with standards and consistency of practice for waitlist and scheduling, budget management, key performance indicators and reporting requirements will be reviewed and confirmed.

Agreements with spoke sites will be introduced to ensure transparent communications between host HHS and spoke HHS. Agreements with spoke sites will document volumes of service activity, roles and responsibilities of onsite genetic counsellor (where relevant) and service support requirements including accommodation and administration.

Objectives

1. Contribute to the establishment of a national clinical genetic policy position.
2. Develop responsive state policy that reflects national policy direction regarding genetic services.
3. Improve Service Agreement with MNHHS regarding GHQ services to clarify purchasing intentions, funding, reporting and performance indicators.
4. Improve collaboration between GHQ and services and providers, across the care continuum, to support coordinated care across the networked service system including introduction of service agreements between GHQ services and spoke HHS sites.

No.	Priority actions	Responsibility
1.1	Contribute to the development of the National Health Genomics Policy Framework 2017-2020 regarding genetic services	Health Innovation, Investment and Research Officer (HIIRO) and HHS
1.2	Analyse GHQ purchased activity compared to actual service activity over a three year period to inform review of Service Agreement	DoH - Healthcare Purchasing and System Performance, SPB, ODG and MNHHS Health funding Analysis
1.3	Partner with Healthcare Purchasing and System Performance Branch regarding (pending) recommendations from the 2016 review of designated Statewide services regarding funding, activity and performance measures	MNHHS
1.4	Align GHQ practice with the principles and business rules contained in the Department of Health's Specialist Outpatient Services Implementation Standard (2016)	Health Improvement Unit (HIU), MNHHS and GHQ

No.	Priority actions	Responsibility
1.5	Develop Statewide Clinical Prioritisation Criteria for outpatient genetic health services to support assessment of patients across Queensland based on urgency	DoH-HIU
1.6	Align data collection practices with the patient level data set specification contained within the Queensland Health Non Admitted Patient Data Collection	DoH-HIU and MNHHS
1.7	GHQ will develop service agreements with HHSs where GHQ provides spoke services to describe frequency, volume and type of GHQ services, reporting arrangements and room/equipment requirements to better enable effective delivery of GHQ services statewide	MNHHS Health Funding Analysis and Legal and GHQ

No.	Actions over the next five years	Responsibility
1.8	Conduct a supplementary review of activity and costing methodology to assess rigour associated with service activity and pathology testing components within GHQ services	DoH - HPSP and GHQ
1.9	Advocate for the inclusion of pathology testing in the Activity Based Funding allocation by the Independent Hospital Pricing Authority	DoH - HPSP and GHQ
1.10	Advocate the introduction of a greater number of clinically indicated genetic tests to the Medicare Benefits Schedule that demonstrate clinical utility and cost effectiveness	Strategy Policy and Planning Division
1.11	Increase transparency of performance information by publishing statewide quarterly statistics on the Hospital Performance website	GHQ and Clinical Excellence Division

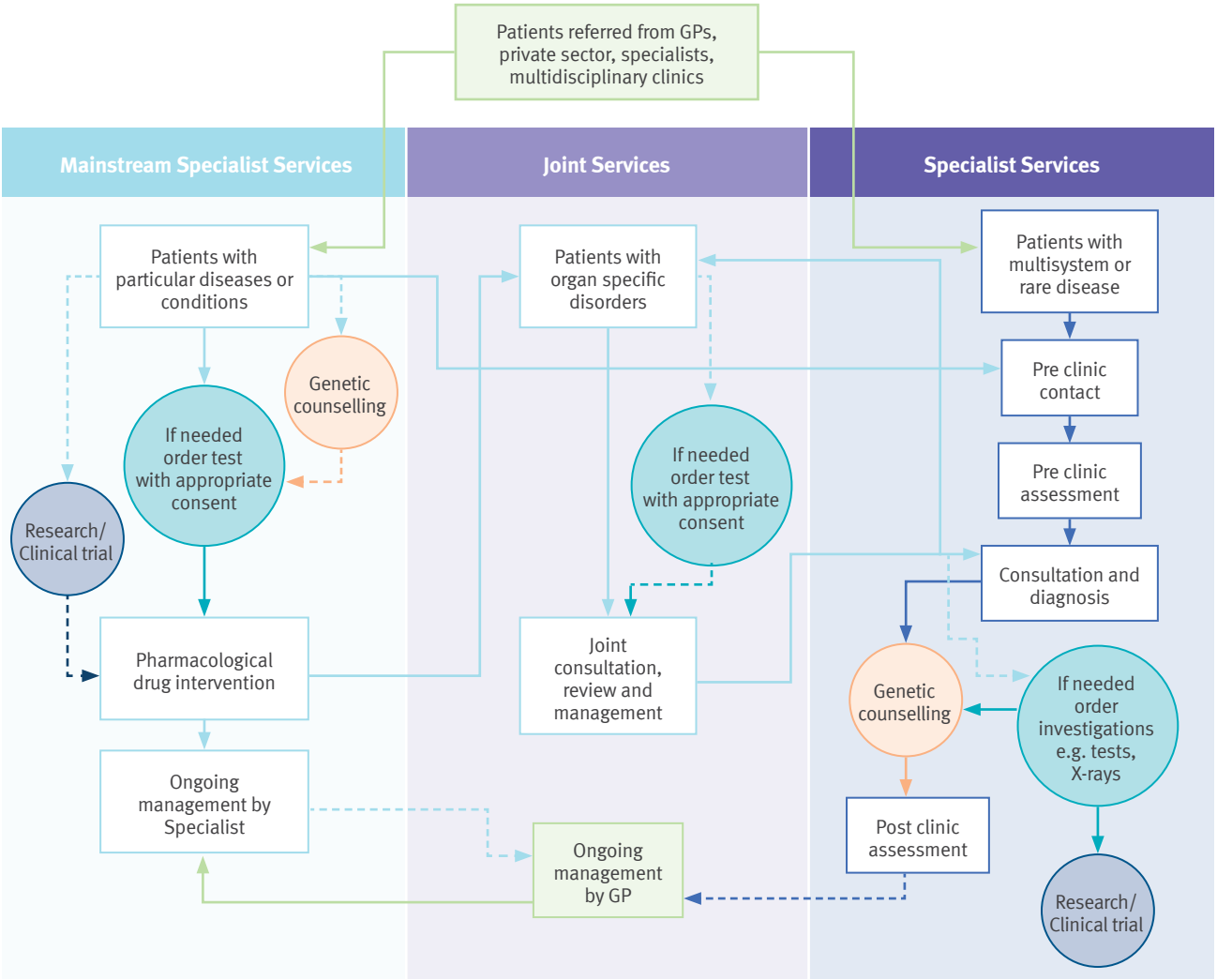
5.2 Service Direction 2: Queenslanders, regardless of where they live, will benefit from coordinated genetic services

Queenslanders will have timely access to sustainable genetic services, regardless of where they live. This will be achieved by enhancing GHQs specialist workforce capacity to deliver services via a networked coordinated statewide service system. GHQ will increase clinical geneticists and counsellor services across sites through increasing telehealth and face to face appointments.

MNHHS is investigating the establishment of a statewide Genetic Health Institute on the Herston Campus to support a coordinated network of genetic services across Queensland. The institute could provide a statewide service that delivers clinical services including multidisciplinary case management using telehealth technology, education programs, and research. The Institute will also provide a venue for advanced teaching programs and industry partnerships. The built infrastructure will support best practice patient care, research and education.

The preferred service pathway depicted below will be further developed to provide a consistent approach to the development of joint services and to build mainstream capability across hub and spoke services to implement models based on best practice. The entrance points for genetic services across mainstream, joint and specialist GHQ services will be clarified. There will be clear stratification and standardisation of processes for patients dependent on their initial diagnosis. There will also be gradual standardisation of the consent process across mainstream service areas and genetic testing criteria to ensure evidence-based care. Overtime, joint clinics will be expanded in both speciality and service locations. GHQ will take a lead role strengthening integration between genetic, mainstream and other services including primary care, broadening genetic knowledge across everyday clinical practice for patient centred care.

Figure 3: Genetics preferred service pathway



Objectives

1. Increase capacity of GHQ to deliver safe and sustainable services to all Queenslanders as close to home as possible.
2. Develop a coordinated and networked service model to deliver safe and sustainable genetic services as close to home as appropriate.
3. Enhance capacity and capability of services (HHSs) to introduce genetic services locally through joint clinics and mainstream models of care.
4. Enhance genetic information sharing and communication via uptake of digital health technologies.

No.	Priority actions	Responsibility
2.1	Develop a workforce planning strategy to determine future workforce requirements to deliver service directions of this Plan	DoH Workforce Planning, MNHHS Workforce planning and GHQ
2.2	Through normal budgetary processes incrementally increase capacity of the GHQ workforce to improve to better meet demand and alignment with the workforce recommendations suggested by the Health Genetics Society of Australia Special Interest Group	MNHHS
2.3	Establish genetic counsellor position/s in Northern Queensland	GHQ
2.4	Investigate the feasibility of establishing a genetic health services hub site at GCUH	GHQ and GCUH
2.5	Enhance capacity of GHQ to better respond to current and projected genetic service demand in areas of need as informed by outpatient long waits and geographic locations with limited services including: • long wait clinics: cardiac, cancer and general clinics • geographic need: Gold Coast, Torres and Cape, North West, South West, Cairns and Hinterland, Central Queensland and Mackay HHS[3]	MNHHS GHQ and other HHS
2.6	Conduct a business requirement assessment of GHQs information needs, and perform a gap analysis to determine the feasibility of the current KinTrak system in meeting future functional requirements.	GHQ and GCUH
2.7	Undertake a review of the NSW Strategy Health Genomics Strategy (in development) to assess the impact of: • service volume: cross-border flows on demand for GHQ services • funding arrangements • pathology testing	DoH-CSD, MNHHS and GHQ

[3] Source: Informed by Background Paper 3: Service Activity and trends. Table 4: Access to genetic services per 100,000 population based on the number of OOS in 2014-15 and total population by HHS for 2014.

No.	Actions to be achieved over the next five years	Responsibility
2.8	Evaluate existing joint clinic arrangements (cancer, cardiac and renal) and expand access to joint clinics in HHSs where there is service need for these specialities	GHQ and HHS
2.9	Investigate the feasibility of establishing hub site at LCCH to enhance delivery of statewide genetic health services for children	GHQ and CHQ
2.10	As new capacity becomes available, increase telehealth and face to face service activity at Gold Coast, Townsville, Cairns, LCCH and Sunshine Coast	GHQ and HHS
2.11	As new capacity becomes available, expand the volume and range of joint clinics including: adult familial cancer clinic services, endocrinology, neurology, maternal foetal medicine, immunology, ophthalmology and paediatrics	GHQ and HHS
2.12	Investigate the low utilisation of GHQ services by Aboriginal and Torres Strait Islander peoples and Culturally and Linguistically Diverse populations	GHQ
2.13	In line with developing national policy direction document clinical standards of service delivery to enable safe and sustainable advancement of genetic services in primary care, joint clinics and mainstream areas	GHQ and HIIRO
2.14	Enhance existing and investigate alternative workforce models to improve access to services including: • specialist telehealth models • genetic counsellor trainees • trainee clinical geneticists • nursing and other allied health trained in genetics • administration upskilling to support general pedigree, pathology follow up, data entry and reporting	GHQ
2.15	Explore expanded scope of practice for experienced genetic counsellors to support: • education of mainstream services in the genetic components of disease • involvement in the interpretation of genetic variants as part of a Multi-Disciplinary Team • working as laboratory-based genetic counsellors	GHQ
2.16	Through normal budgetary processes further increase capacity of GHQ workforce to incrementally advance towards workforce guidelines. The current guidelines suggest the need for the following[4]: • total 21 FTE clinical geneticists • total 21 FTE genetic counsellors • total 16 FTE administration	MNHHS

[4] Source: Human Genetics Society of Australasia Special Interest Groups. The Health Workforce: Productivity Commission Issues Paper. 2005 [Accessed April 2016]; Available from: http://www.pc.gov.au/inquiries/completed/health-workforce/submissions/sub097/sub097.pdf

5.3 Service Direction 3: Innovation and research will drive advancements in genetic health services across Queensland

Consideration will be given to the establishment of an expert panel to provide strategic direction to genomic research and development so that Queensland is at the forefront of evidence-based genetic healthcare. The expert panel could provide strategic direction on the policy, ethics and legal implications of this rapidly evolving field and importantly, the translation of research to clinical practice.

The expert panel could also provide the platform to clarify the role and linkages between the expert panel, Australian Genetics Health Alliance, the Queensland Genomics Health Alliance (QGHA) and the proposed Genetic Health Institute as they evolve over time.

GHQ will continue to lead and actively participate in research to advance clinical practice. Through establishing a virtual network across Queensland research and innovation in clinical genetics will be advanced.

Transformed preferred service models will be supported through the proposed development of a Genetic Health Institute on the Herston Campus. Partnering with patients, universities and research institutions, the Institute will be recognised as a global leader in genetic health research, education, training and scientific studies.

Objectives

1. Establish robust mechanisms to provide coordinated advice and direction to support effective rapid translation of genetic based discoveries into healthcare practice.
2. Advance research in genetic health service advancements in partnership with universities, research partners and other health service partners.
3. Increase capability of broader HHS service system to participate in genetic research.

No.	Priority actions	Responsibility
3.1	Investigate the establishment of an expert panel to provide insight to: • the translation of whole genome and exome sequencing research into clinical practice • storage of DNA for research purposes and the consent models underpinning use of information • ethical and legal implications of whole genome/exome sequencing, particularly in regards to 'incidental findings' including consideration of how this plays out in the move towards eHealth	DoH-HIU, SPPD, ODG, and MNHHS and GHQ
3.2	Actively partner with research institutions, universities and alliances to advance genetic and genomic research including opportunities to work with broader HHS service system	GHQ, MNHHS and HHSs
3.3	Build on existing partnerships to support joint appointments with universities across all professions	GHQ and MNHHS Business Units
3.4	Investigate opportunities for joint appointments with universities to support and promote research agenda	GHQ and MNHHS Business Units

No.	Actions to be achieved over the next five years	Responsibility
3.5	Work in partnership with Queensland Genomics Health Alliance to accelerate implementation of clinical genomics into Queensland's health system	GHQ and HIIRO

5.4 Service Direction 4: Improving knowledge, health literacy and capability for informed decision making

Targeted communication and engagement activities will improve the knowledge of primary care, mainstream services, and health literacy of consumers that will clarify expectations, and describe the role and function of genetic services.

GHQ will target education to mainstream service providers including primary care to discuss advancements of genetics in mainstream services, promote service delivery models, provide education regarding optimal use of genetic testing, and provide resources to support service provision e.g. hotline for support in diagnosis and interpretation of genetic testing results.

GHQ will provide education to primary health care and external referrers to clarify the role of GHQ, promote screening such as thalassemia screening in ethnic populations and clarify referral requirements for specific conditions.

GHQ will develop standardised guidelines, protocols, frameworks to enhance capability and educate mainstream capacity and decision making including the genetic clinical service delivery framework, genetic testing criteria and competencies framework e.g. to assist mainstream services when requesting, interpreting, and managing patients at risk of a genetic disorder. The elements will consider cost versus clinical utility of tests, the consent process and support for interpreting and communicating findings, and the consent processes for individuals and families with a positive family history for a specific condition for asymptomatic and predictive genetic testing.

Objectives

1. Increase GHQ service presence and awareness across HHSs and primary care.
2. Embed health literacy into genetic health service system through effective and targeted engagement and communication and the establishment of a repository of information.
3. Develop protocols, standards and other materials to support service delivery and develop capability in mainstream areas.
4. Increase capacity and capability of clinicians to request, interpret and communicate genetic tests, with appropriate consent (tests only ordered by appropriately trained and qualified health professionals).

No.	Priority actions	Responsibility
4.1	Develop a stakeholder and engagement strategy to provide a consistent approach to engagement and communication activities with stakeholders (e.g. clinical networks, primary health care and community). The strategy will assist to deliver key messages and support the development of relationships	GHQ and MNHHS
4.2	Develop an education programme to promote GHQ services to mainstream services, primary health care and external referrers including Aboriginal and Torres Strait Islander services including community controlled health services, Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care and Culturally and Linguistically Diverse populations	GHQ, PQ, A&TSI Branch and MNHHS
4.3	Redevelop the GHQ webpage to provide comprehensive service information including clinic locations and types, indicative waiting times and other pertinent information available to referrers and patients	GHQ and MNHHS
4.4	Enhance the repository of information available on the GHQ webpage to address the information needs of referrers and patients including: • Diagnosis and management of disease e.g. referral guidelines, eligibility criteria, pathways, frequently asked questions (FAQs) • Patient health literacy e.g. fact sheets, FAQs	GHQ and MNHHS
4.5	Develop standardised guidelines, protocols, frameworks to educate mainstream capacity and decision making	GHQ, Pathology Queensland (PQ), MNHHS Business Units, DoH-HIU

5.5 Service Direction 5: Queensland residents will have access to genetic testing services that are cost-effective and based on clinical need.

Advancing genetic health services in Queensland will be dependent on corresponding advancements in genetic testing. GHQ will continue to partner with Pathology Queensland to ensure advancements in GHQ services are supported by timely genetic testing services that are efficient, cost effective and high quality having undergone a rigorous evaluation processes.

Objectives

1. Enhance capability of Pathology Queensland systems through implementation of findings from costing and pricing project to enable accurate and transparent reporting and billing of genetic tests.
2. Improve collaboration between GHQ and PQ to establish criteria to support safe and cost effective growth of genetic services.
3. Improve information available for Queenslanders and referrers regarding genetic testing.

No.	Priority actions	Responsibility
5.1	Review current workforce levels with recommended accreditation benchmarks and develop a strategy to address the gaps	PQ
5.2	Develop statewide genetic testing criteria which will provide a referral guideline for genetic diagnosis by indicating the clinical features of the genetic condition and the types of referrers expected to order the test	PQ, GHQ, Clinical Excellence Division, Expert Panel/HIIRO
5.3	Establish an agreed set of baseline measurements for common genetic testing turnaround timeframes. This will include consideration of: a) Publication and communication of expected waiting times to referrers and patients by testing modality on the PQ homepage b) Explore alternative pathways when at peak capacity (i.e. send to another laboratory)	PQ
5.4	PQ to review internal processes to improve: a) Genetic testing price transparency: prices to be available on website b) The cost of genetic tests: regular benchmark activities to ensure fairness of price c) Pathology report: communication strategy to ensure visibility of waiting times and turnaround timeframes for reports	PQ
5.5	Implement findings of 2016 costing and pricing project to ensure ongoing alignment between costs and prices in accordance with the principles of cost recovery and transparency	PQ
5.6	• Ensure tender documentation for the new Laboratory Information System (LIS) includes interoperability as a mandatory requirement to ensure interface between the proposed system and KinTrak. The proposed LIS should also include requirements for billing and cost recovery	PQ

Implementation, monitoring and review

Implementation

Implementation of this Plan will be led by GHQ in a staged process to allow ongoing refinement over the next five years. At the local level, the Plan will guide the health service priorities of the program areas and will be integrated into their local operational plans. Critical success factors will be considered in the establishment of the implementation plan.

MNHHS Executive Team will provide expert guidance to the implementation process.

All operational plans relating to GHQ services should align with the service directions and service objectives in this Plan. For the actions, each program nominated as responsible is required to lead the action in the timeframe proposed.

The Plan will also assist GHQ to establish a platform for discussion and negotiation with Department of Health, MNHHS, HHSs and other agencies around particular issues. GHQ commits to working in partnership with MNHHS to support and strengthen sustainable solutions to respond to the needs of adults and children across Queensland providing care as close to home as possible.

Risks to successful implementation

The success of the Plan relies on each responsible party determining an approach to implementing the objectives and actions aligned with the service directions. The key risks of not achieving the actions include:

- inability to accurately inform service enablers, including infrastructure, workforce, support service
- insufficient future resources allocated to GHQ to deliver actions resulting in inability to meet health service demand
- information technology requirements
- missed opportunity to leverage other Queensland initiatives relating to genomics
- inability to plan the allocation of future resources.

Resource implication

It is important to acknowledge that we operate in an environment of competing health needs and finite resources.

This process of planning considered the resource implications of the actions. Actions were prioritised based on available information regarding the ability to resource or negotiate for resources for actions and prioritised service needs.

It is understood that whilst this Plan reflects prioritised service actions to support evolution of Statewide genomic service needs, service development will require resourcing over time through organisational budgetary processes.

Monitoring, reporting and review

Monitoring, evaluating, reporting and reviewing implementation of the Plan, including reporting on progress towards achieving the identified objectives will be coordinated by GHQ.

Given the rapid change and growth in health needs the Plan will be monitored and reported on an annual basis (end of financial year) in line with operational plan reporting. These processes will allow changes in direction during the implementation of the Plan to ensure ongoing relevance and provide information upon which future service planning may be based. This will also allow the findings and recommendations of statewide policy to be considered and actions updated as required.

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