GENETIC HEALTHWA

# SERVICE PLAN

# 2024 – 2029

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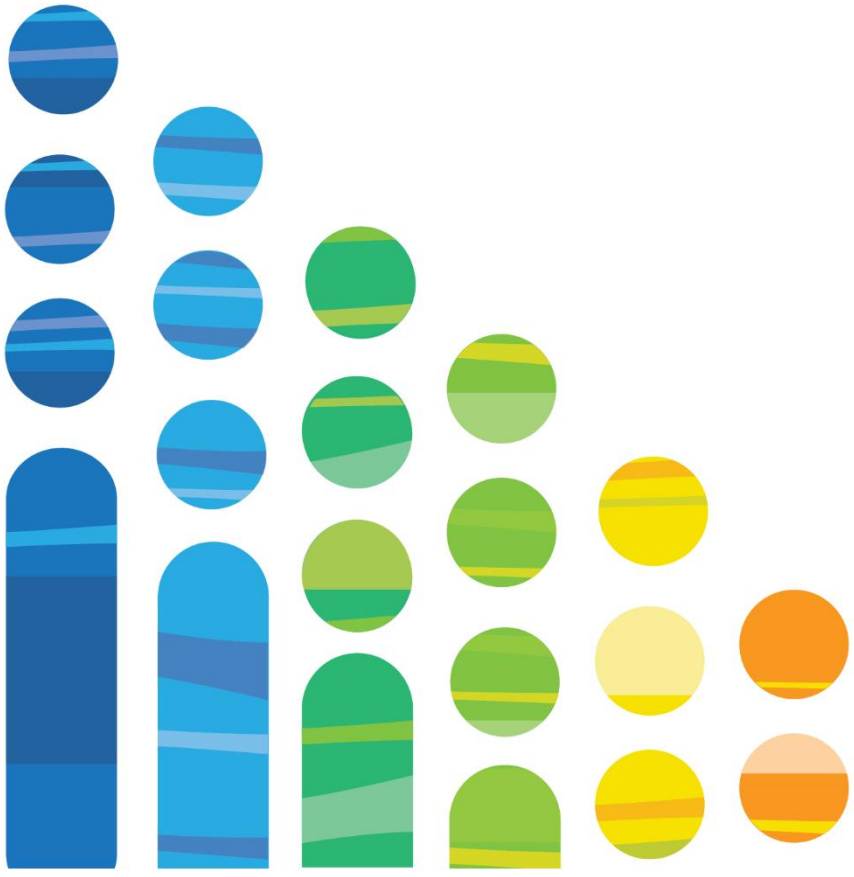

Understanding GENETICS for you and your family

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To be included in the final Plan

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To be included in the final Plan

**Figure 1: A summary of the service directions and underlying objectives of the Plan.** – To be included in the final Plan

# Introduction

Genetic Health Western Australia (GHWA) was established in 1988 as the Genetic Services of Western Australia. Due to the historic association of clinical genomic specialty services with pre- and post-natal care, the service is part of the Women and Newborn Health Service (WNHS), which was incorporated into the North Metropolitan Health Service (NMHS) in 2016. GHWA is currently located at King Edward Memorial Hospital (KEMH) and began formally operating as GHWA in January 2024.

GHWA provides a clinical genomic specialty service throughout Western Australia (WA) that encompasses the diagnosis, management, and support of individuals with, suspected of, or at an increased risk of themselves or a child having a germline genetic condition. Given the increasing utility of genomic technology and knowledge in healthcare, GHWA's role as a central source of genomics expertise is invaluable for helping to implement genomics within the Western Australian health system. The rapid growth in genomic medicine over recent years has led to an increase in demand for the clinical genomic specialty services provided by GHWA from both health professionals and consumers across WA.

Since its establishment, GHWA's consumer base has evolved from being primarily comprised of obstetric and neonatal patients to include adults at risk of familial cancers and children and adults with rare genetic conditions, adding to the complexity of the services GHWA provide. Purposeful and adaptive service planning is needed to enable GHWA to manage future demand in a timely manner and consistently provide equitable, person- and family-centred clinical genomic speciality services. GHWA's inaugural service plan, the "Genetic Health Western Australia Service Plan 2024-2029" (the Plan), has been developed to assist GHWA in achieving this goal. The Plan aims to facilitate the provision of an equitable service able to appropriately support the emerging genomic healthcare needs of consumers throughout WA. As such, it informs the future service profile of GHWA and outlines what actions, enablers and partnerships are required to ensure services are delivered efficiently and equitably and address the diverse needs of its stakeholders.

## Developing the Plan

The development of the Plan was a collaborative undertaking between GHWA[1] and the Office of Population Health Genomics at the Western Australian Department of Health (Department of Health), and as such was co-sponsored by the NMHS and the Department of Health. A co-design approach involving a broad range of stakeholders was taken to ensure a balance of experiences, perspectives, and ideas to inform the future service delivery of GHWA and develop a plan that will best address the needs of Western Australians and support the future demand for genomics in WA.

A GHWA Service Plan Co-Design Team (Co-Design Team), which was co-chaired by a lived experience consultant, was established to bring together stakeholders with lived and learned experience of GHWA to collaborate throughout the development of the Plan. As GHWA is a

[1] All planning and consultation for the development of the Plan occurred whilst the service was operating as the Genetic Services of Western Australia; however, this document refers to the service as Genetic Health Western Australia or GHWA to reflect the change in name effective 08/01/2024.

service operating throughout WA with a wide range of stakeholders, the Co-Design Team prioritised engaging with as many different stakeholders as possible by using a range of engagement methods (including surveys, focus groups, interviews, and workshops) and recruitment strategies. Over 300 stakeholders shared their insights to inform the Plan (Figure 2), including:

- GHWA consumers and carers
- Staff from GHWA
- Representatives from patient organisations
- Medical specialists, including general practitioners (GPs) and other primary care providers
- Representatives nominated by the Chief Executives of most Health Service Providers (HSPs) including the WA Country Health Service (WACHS), East Metropolitan Health Service (EMHS), South Metropolitan Health Service (SMHS), Child and Adolescent Health Service (CAHS), and PathWest Laboratory Medicine WA (PathWest)
- Members of the WA Genomics Strategy Implementation Committee


**Figure 2: Stakeholder engagement activities undertaken for the development of the Plan.**

For more details of the co-design approach and stakeholder engagement conducted, please see Appendix 1.

In addition to the stakeholder engagement activities, a desktop review of relevant policies, strategies, and academic literature, as well as profiling of the current service (including service arrangements and current activity) was undertaken to inform the Plan and shape the future directions.

## Planning context

The Plan was informed and guided by several key state and national policies and strategic frameworks (Figure 3).


**Figure 3: Planning context for the Plan, including relevant state and national documents.**

As GHWA is a service governed by the NMHS, yet delivers services throughout WA, the planning context is influenced by the strategic priorities of both the NMHS and Department of Health, including the:

- *North Metropolitan Health Service, Our Strategic Plan: 2020-2025: One team, many dreams. One integrated NMHS*
- *WA Health Strategic Intent 2015 – 2020*
- *WA Health Clinical Services Framework 2020 Addendum*
- *WA Health Digital Strategy 2020-2030*
- *Sustainable Health Review: Final Report to the Western Australian Government*
- *Independent Review of WA Health System Governance Report*

The *National Health Genomics Policy Framework 2018-2021* (currently under review) and the Human Genetics Society of Australasia (HGSA) *Clinical Genetic Services Framework 2024* are key national genomics policy and clinical frameworks that have also been considered in the development of the Plan.

The *WA Genomics Strategy 2022-2032: Towards precision medicine and precision public health* (the WA Genomics Strategy) outlines a coordinated and strategic approach to guide the future delivery of health genomics in WA and the development of this Plan is one of many key actions in the first implementation plan for it. The WA Genomics Strategy describes five strategic priority areas and goals to guide the efficient, effective, ethical and equitable translation of genomics into the Western Australian health system and valuably contribute towards the delivery of precision medicine and precision public health.

The WA Genomics Strategy is designed to facilitate the application of genomic knowledge and services to enable precision medicine and precision public health approaches, as well as the associated health outcomes and policy implications. The WA Genomics Strategy has a broad

remit, capturing all uses of genomics for precision medicines and precision public health purposes. This includes genetic and genomic tests, and therapies or interventions utilising genomic information which have increasing applicability to a range of medical disciplines and as such are delivered by a range of health service providers across the Western Australian health system at an individual or population level (see Appendix 2). The clinical genomics specialty services provided by GHWA are one part of this broader application of genomics in WA.

Responsibility for the implementation of the WA Genomics Strategy is shared amongst stakeholders across the Western Australian health system, with system-wide stewardship and leadership provided by the Department of Health and oversight provided by the WA Genomics Strategy Implementation Committee. However, as the only clinical genomics speciality service in the Western Australian health system, GHWA is one of the key implementation partners (see Appendix 3). The Plan aims to guide GHWA in taking the first steps of implementation, with further action and sustained support necessary to continue progress towards achieving the WA Genomics Strategy's ambitious aims in subsequent years.

# Service profile

## Position within the Western Australian health system

The *Health Services Act 2016* (the Act) outlines the structure for the public health system in WA. GHWA is part of the NMHS, one of the eight HSPs formed under the Act (Figure 4). The KEMH, the maternity and gynaecology units at Osborne Park Hospital and other specialist services form the WNHS within NMHS. GHWA is situated at KEMH, and therefore the clinical governance for GHWA is provided by the WNHS and the NMHS. Each HSP is assisted by the Department of Health through a range of systemwide plans and policies and service agreements to deliver healthcare services to a catchment area defined within the Act. Despite being part of one HSP, GHWA provides clinical genomic specialty services to people throughout WA, with some services facilitated through collaborations with other HSPs.

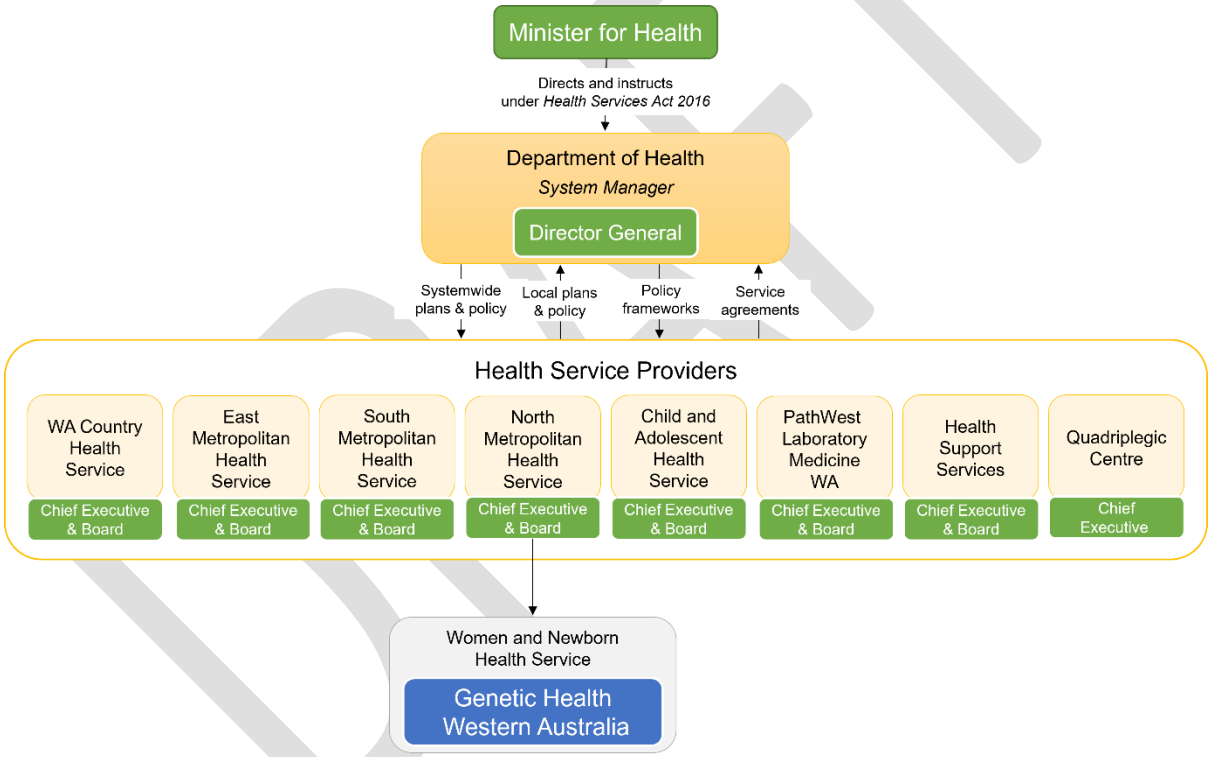


**Figure 4: Organisational structure of the Western Australian health system as set out by the *Health Services Act 2016*.**

## Service model

GHWA receives referrals for individuals and families with, suspected of, or at an increased risk of themselves or a family member having a genetic condition from health professionals, as well as self-referrals, across WA. GHWA offers comprehensive clinical assessments, genetic counselling, and informed consent to these individuals, and facilitates access to genomic testing services. GHWA's consumer support extends beyond individual consumers to

encompass at-risk family members, carers, and their extended healthcare team. This includes the provision of information resources, assistance with sharing genomic test results with family members and, in some cases, direction to other services for further information and support. However, this does not currently extend to broad psychosocial care or ongoing follow up for all consumers. Like clinical genomic specialty services in other states in Australia at this time, GHWA provides limited follow-up for consumers, with most cases deactivated once the individuals are directed back to their referrers and provided with specialised advice for ongoing care following receipt of genomic testing results. However, consumers are advised they are welcome to re-contact GHWA about questions or concerns in the future, and some consumers are seen at GHWA when needed at a later life stage.


**Figure 5: GHWA clinic locations across WA.**

GHWA's central hub is located at KEMH. Outpatient clinics and inpatient ward consultations are provided at both KEMH and Perth Children's Hospital (PCH). GHWA also deliver outpatient services at selected metropolitan and regional outreach clinics (noting that there are some health regions within WA that do not host a dedicated outreach clinic). The locations and scheduling of GHWA's outreach clinics are depicted in Figure 5. Clinics that GHWA collaboratively deliver with health professionals in other HSPs are described under 'Collaborative work'.

Clinics are provided in multi-modal format with telehealth and phone appointments offered where clinically appropriate. Along with outreach clinics, telehealth and phone appointments help to ensure that services are delivered as close to home as possible.

GHWA provides services for adults and children across 3 service streams: Obstetrics and General Genetic Services (OGGS), Genetic Paediatric Services (GPS), and the Familial Cancer Program (FCP). Whilst these service streams were historically established to meet demand for clinical genomic specialty services at that time, it is possible this 3-stream model may not remain fit for purpose as genomics evolves in the future.

The OGGS service stream offers services to adults at risk of or affected by a genetic condition, as well as adults prior to or during pregnancy if they are at increased risk of having a child with a genetic condition. This includes adults impacted by cardiac and renal genetic conditions, although there has been some work over recent years to develop these areas into a separate service stream.

The GPS service stream manages children identified with or suspected of having a genetic condition, including those who have congenital abnormalities, are experiencing developmental delay, or have unexplained differences in growth or clinical features. This also includes babies who are identified as likely to have certain genetic conditions through WA's Newborn Bloodspot Screening Program.

The FCP accepts referrals for patients who have or are suspected of having an increased risk of familial cancer. GHWA ensures these individuals are informed of the current cancer screening guidelines and recommendations and have access to regular monitoring procedures. These functions are aided by the Western Australian Familial Cancer Registry, which is coordinated by and housed at GHWA.

Figure 6 shows a diagrammatic representation of many aspects of the services GHWA provide.


**Figure 6: A summary of GHWA's current services.**

## Eligibility criteria and indications for referrals

Referrals to GHWA are triaged based on the criteria outlined below in Table 1. GHWA does not accept referrals for all genetic conditions. Some genetic conditions or cases that are not managed by GHWA include familial hypercholesterolaemia, changes in the *MTHFR* gene (a gene involved with folate metabolism), or individuals who are carriers of an autosomal recessive genetic condition such as cystic fibrosis (noting that couples where both individuals are carriers and are planning pregnancy are eligible for referral).

**Table 1: GHWA referral criteria.**

| Service stream | Referral criteria |
|---|---|
| Obstetrics and General Genetic Services | • Adults who have or are suspected of having a genetic condition.<br>• Adults who are referred due to a sudden cardiac death in the family and are receiving genetic test results (on behalf of the family member who died) and related genetic counselling.<br>• Adults who have a family history of a genetic condition and are considering pregnancy.<br>• Pregnant individuals whose unborn or future child has an increased risk of a genetic condition. |
| Familial Cancer Program | • Adults with, suspected of being at risk, or known to be at risk of an inherited cancer syndrome. |
| Genetic Paediatric Services | • Children identified with or suspected of having a genetic condition, including inherited cancer syndromes. |

## Triage of referrals

Appointments with GHWA are allocated according to urgency (see criteria in Table 2). In the GPS and FCP subspecialities, the initial contact following receipt of a referral commonly takes place via a scheduled phone call during a work-up clinic. This initial phone discussion provides individuals with an opportunity to ask questions and allows GHWA staff to collect family history regarding the reason for referral. Within the OGGS subspecialty, a non-formalised phone call may be made prior to the initial appointment to gather or clarify family or personal history. This information is important to determine the appropriateness of the referral, and to help triage and prepare for those patients who require an appointment.

**Table 2: GHWA referral urgency.**

| Urgency | Timeframe for appointment | Criteria |
|---|---|---|
| 1: Urgent | ≤ 30 days<br>*(Initial contact within 48 hours)* | • A pregnant individual whereby management or treatment decisions may be influenced by genetic testing.<br>• An individual whereby potentially life-saving management or treatment options may be influenced by genetic testing.<br>• A newborn requiring immediate clinical assessment and possibly genetic testing that may influence lifesaving treatment or management options.<br>• An individual who is receiving palliative care. |

| Urgency | Timeframe for appointment | Criteria |
|---|---|---|
| 2: Semi urgent | ≤ 90 days | • An undiagnosed individual who requires a clinical assessment for treatment and management.<br>• Known carrier couples considering pregnancy. |
| 3: Routine | ≤ 365 days | • An undiagnosed individual who requires a clinical assessment for a genetic diagnosis.<br>• An individual whereby a clinical diagnosis has been identified, however a genetic diagnosis may provide more succinct management or surveillance options.<br>• Familial clustering of specific cancers (such as breast or bowel) whereby testing cannot be offered to an affected family member due to death or geographical location.<br>• Pregnancy planning for a couple who are biologically related.<br>• Cascade testing in an unaffected individual. |

## Workforce

GHWA's services are delivered by clinical geneticists (geneticists) and genetic counsellors, supported by clinical officers, administrative and data management staff. A geneticist is a medical doctor specialising in diagnosing and clinically assessing individuals and families affected by, suspected of, or at risk of a genetic condition. Geneticists will assess the consumer's physical attributes, medical and family history to provide individuals and families with information on recurrence and condition management. A genetic counsellor is an allied healthcare professional who helps consumers understand and adapt to the medical, psychological, individual, and familial implications associated with genetic conditions. A genetic counsellor will undertake and interpret personal and family histories, conduct risk assessments, and support individuals and families to make informed and autonomous decisions about their health care. Both geneticists and genetic counsellors educate and provide information on inheritance patterns, testing options, current management or surveillance guidelines, and research opportunities.

Geneticists and genetic counsellors collaboratively deliver clinics, which are all overseen by a geneticist. GHWA's workforce also includes 2 intake support staff known as clinical officers. Clinical officers assist in managing consumer records and gathering comprehensive family history information. Additional clinical staff, administrative support staff, and data or registry manager positions are documented separately in Table 3, which outlines GHWA's current workforce as of January 2024. All GHWA staff are based at KEMH, yet some regularly travel to other locations to deliver certain off-site clinics in the metropolitan area, whilst some share rotational responsibilities for attending outreach clinics.

GHWA are also in the process of recruiting a psychologist (who will provide counselling supervision for genetic counsellors and will also provide counselling to some consumers) and an Aboriginal Health Worker, both of which will be employed part-time at 0.6 full-time equivalent (FTE) hours. These positions are not included in Table 3.

**Table 3: GHWA's current workforce as of January 2024.**

| Role | Staff headcount | Total FTE |
|---|---|---|
| Genetic counsellors | 25 | 20.4 |
| Clinical geneticists | 9 | 6.6 |
| Trainee clinical geneticists | 3 | 3.0 |
| Clinical officers | 2 | 2.0 |
| Clinical nurse specialists | 2 | 1.2 |
| Data managers | 2 | 2.0 |
| Familial Cancer Registry managers | 2 | 1.6 |
| Administration staff | 13 | 12.1 |
| **Total** | **58** | **48.9** |

## Collaborative work

GHWA frequently collaborates with a range of other specialties to provide joint models of care at Fiona Stanley Hospital (FSH), Royal Perth Hospital (RPH), Sir Charles Gairdner Hospital (SCGH), PCH or KEMH. These collaborative clinics are delivered by health professionals from multiple specialities to ensure the care provided to individuals and their family members is timely, holistic, integrated and person-and-family-centred. By involving multiple health professionals with different expertise, these clinics enable mentoring, coaching and knowledge transfer between genomic and non-genomic specialists and thus can help to progress the safe and appropriate integration of genomics into clinical care across a range of medical specialities.

GHWA also supports non-genomic specialists to deliver genomic services by discussing cases with a potential genetic cause and providing advice on the appropriate genomic tests to order, the interpretation of test results, and referral of patients and/or their family members to GHWA. This support is provided through regular attendance at multidisciplinary team (MDT) meetings (at which patients are not present), or through the provision of *ad hoc* advice (including through an on-call service where a geneticist and/or genetic counsellor answer health professionals' queries) and education. It is likely that the number of non-genomic specialists ordering diagnostic testing for their patients will continue to grow as genomic technology becomes increasingly integrated into non-genomic specialties, resulting in rising demand for GHWA's expertise and advice.

Table 4 includes a list of the collaborative clinics and MDTs that GHWA either leads or regularly participates in across the WA health system. In addition to these formalised, regular arrangements, GHWA has developed some agreed patient pathways with other services to support their delivery of person- and family-centred genomic services (e.g. advice on and/or joint appointments with the NMHS Neurosciences Unit regarding predictive testing for neurodegenerative conditions such as Huntington's disease).

**Table 4: GHWA's clinical collaborations as of 2024.**

| Collaboration | Location | Led by |
|---|---|---|
| **Clinics** | | |
| Adult inherited cardiac^ | FSH | FSH |
| Vascular connective tissue disease^ | FSH | FSH |
| Nephrology^ | FSH/SCGH | GHWA |
| Adult cancer surveillance | KEMH | GHWA |
| Inherited gastrointestinal cancer | KEMH | GHWA |
| Dermatology | PCH | GHWA |
| Ophthalmology | PCH | GHWA |
| Paediatric inherited cardiac* | PCH | GHWA |
| Undiagnosed Disease Program | PCH | GHWA |
| 22q11 deletion disorder & CHARGE syndrome | PCH | PCH |
| Achondroplasia | PCH | PCH |
| Endocrine bone | PCH | PCH |
| Paediatric cancer surveillance | PCH | PCH |
| RASopathy# | PCH | PCH |
| Fabry disease | RPH | RPH |
| **MDTs** | | |
| Vascular connective tissue disease^ | FSH | FSH |
| Adult inherited cardiac^ | FSH | FSH |
| Breast cancer | FSH | FSH |
| Nephrology^ | FSH/SCGH/PCH/RPH | GHWA |
| Maternal Foetal Medicine | KEMH | KEMH |
| Gynaecology-Oncology | KEMH | KEMH |
| Ophthalmology | Harry Perkins Institute | Lions Eye Institute |
| Molecular Tumour Board | PathWest | PathWest |
| Paediatric oncology | PCH | PCH |
| TCT/PIM/Haem | PCH | PCH |
| Adult inherited cardiac | RPH | RPH |
| Breast cancer | RPH | RPH |
| Breast cancer | SCGH | SCGH |

^Clinics and MDTs are linked
*Established in early 2024
#GHWA's involvement commenced in early 2024

## Genomic testing

Genomic laboratory testing is a core enabling tool of clinical genomic specialty services (see Box 1). GHWA predominantly orders genetic and genomic testing (e.g. deoxyribonucleic acid (DNA) sequencing, cytogenetic analyses) from PathWest, with whom GHWA work collaboratively to maximise the alignment between genomic testing and clinical genomics. This includes helping to assess and classify genetic variants detected through genomic testing. Consequently, the scope of genomic testing services requested by GHWA is influenced by the testing repertoire and capacity of PathWest. However, testing is sometimes sought from external organisations when required, such as when a particular test is not offered by PathWest or when a specific turnaround time for the result is necessary.

Historically, analyses of genes using a technique called DNA sequencing was limited to analysis of the DNA code of only a relatively small section of a single gene. This approach was called “genetic testing”, and it was applied to certain genes known to be causative of specific diseases if they contained particular changes in their DNA code. As multiple genes became identified as causing the same or very similar clinical features and diseases, it became difficult for healthcare professionals to accurately select the most appropriate single gene or part of a gene for DNA sequencing, to thereby provide individuals with a genetic cause or diagnosis. If a genetic cause was not established from the initial DNA sequencing of a region/s of a gene, a subsequent gene test might have been selected in an attempt to yield a genetic answer, adding cost and time.

Due to the significant advances in DNA sequencing technology and data analysis, genetic testing has substantially evolved towards genomic testing. Genomic testing enables with a single test the analysis of multiple genes, all genes (an "exome", approximately 1.5%-2% of a genome), or even the entire genome (all of a human’s DNA code, including all known genes and other regions of DNA that can influence genes). Types of genomic testing include diagnostic, predictive, prognostic, cascade, and reproductive carrier testing. Testing for cancers can be germline or somatic. The knowledge gained from these different types of genomic testing facilitates a range of personal, familial and health system benefits, with the appropriateness of using each type of test dependent on the health scenario.

Whilst the cost of genomic testing has rapidly decreased over time, currently the price can be higher than many single gene tests. However, the timeliness of genomic testing and its greater likelihood of providing information with clinical utility makes this approach desirable in an increasing number of treatment and management circumstances, and indeed can provide economic efficiencies to healthcare systems. As such, genomic testing is now routinely offered to a growing number of Western Australian consumers.

**Box 1: Genomic testing by DNA sequencing.**

# Population serviced

The size of Australia's population is captured every 5 years in the national Census. In between Census dates, estimates of the resident population are created by several sources, including the Australian Bureau of Statistics (ABS) and government agencies. The Department of Health uses population projections that were created by the Department of Planning, Lands and Heritage known as WA Tomorrow. These projections were created as 5 bands (A to E) with band C, which represents the median forecast agreed by the Western Australian Department of Treasury and underpins the Department of Health's activity modelling.

GHWA is responsible for planning and delivering clinical genomic specialty services to the entire Western Australian population across all age groups and health regions. Between 2017 and 2023 the estimated Western Australian population grew by approximately 11.3% to 2,878,563. In the year ending 30 June 2023, WA had the fastest population growth rate out of all Australian jurisdictions at 3.1%[2]. In the 2021-22 financial year, the Greater Perth region increased by 1.5% (32,200 people) whilst the rest of the state increased by 1.0% (5,800 people).

Based on the endorsed *WA Tomorrow Population Report No. 12*, the Western Australian population is estimated to grow by 15% from the 2022 population to 3,199,300 by 2029 and 24% to 3,567,000 by 2036[2]. However, it is expected referrals to GHWA will increase at a faster rate as local awareness of genetic conditions grows and more widespread adoption of genomic technologies in routine clinical practice of non-genomics specialties occurs. In addition, more genetic conditions are increasingly being identified as new technologies emerge and methodologies evolve, and confirming a genetic diagnosis becomes increasingly relevant as more interventions and treatments targeted towards the genetic cause of disease are developed. These developments are likely to further increase demand for GHWA's services.

The incidence of disease in the community also affects the population eligible for referral to GHWA and in turn, service demand.[3] For example, the incidence of cancer is expected to continue increasing with the growing size of the population, an ageing population, and advancements in imaging and diagnostic capabilities, which can detect earlier or more indolent forms of cancer. In 2019, 13,925 cases of cancer were diagnosed in WA, equivalent to an incidence rate of 463.9 cases per 100,000 persons. Whilst hereditary cancers only account for 5-10% of all cancers, the growing incidence of cancer amidst a growing population is expected to lead to an increase in the number of referrals to GHWA's Familial Cancer Program over time.

People living with a rare disease will remain a core population group serviced by GHWA given the complex nature of their conditions. Rare diseases can affect multiple systems of the body, which leads to various challenges and unmet needs when clinical specialties predominantly focus on single or localised organ systems. Hence, these consumers normally benefit from multidisciplinary care, which can be coordinated by GHWA. Around 8% of the Australian population is estimated to be affected by a rare disease, 80% of which are genetic in nature[4]. There are more than 7,000 known rare diseases and the majority (75%) affect children[5].

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[2] Australian Bureau of Statistics (2023) National, state and territory population, ABS Website, accessed 13/03/2024
[3] Australian Institute of Health and Welfare (2023) Cancer data in Australia, AIHW Website, accessed 22/02/2024
[4] Commonwealth of Australia as represented by the Department of Health (February 2020) The National Strategic Action Plan for Rare Diseases
[5] Murdoch Children's Research Institute (2024) Rare genetic disorders, MCRI Website, accessed 15/02/2024

Based on WA's estimated population of 2,878,563 in the year ending June 2023[6], approximately 230,285 Western Australians are living with a rare disease, including 48,798 children (aged 16 years and under). Currently, GHWA only services a small fraction of the estimated population affected by a rare disease as these conditions are normally difficult for health professionals to identify due to lack of familiarity, rarity of the disease, and highly complex symptoms. Limited awareness of GHWA and the services it offers may also play a role in the observed referral numbers being lower than expected. However, as genomic technologies become more precise, rare diseases are being discovered more regularly. This, in conjunction with increased awareness of GHWA's services and enhanced data collection on rare diseases (see *National Strategic Action Plan for Rare Diseases*), is likely to increase the size of the population eligible for referral to GHWA and therefore demand on the service.

Other important population groups serviced by GHWA include Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CaLD) backgrounds. In 2021, Aboriginal and Torres Strait Islander people made up 3.3% of the Western Australian population, a 16.7% increase from the previous 2016 Census[7] with continued population growth forecasted through to 2031[8]. The most populous areas in WA for Aboriginal and Torres Strait Islander people include Geraldton, Kalgoorlie, and Rockingham[9] where GHWA has already established outreach clinics. These clinics present the opportunity to have an increasingly important role in delivering care closer to home and improving engagement with consumers, particularly as the Aboriginal and Torres Strait Islander population grows.

Additionally, WA is home to the highest proportion of people born overseas (32.2%), compared to other Australian jurisdictions[7]. Whilst the top 10 birthplaces remained the same in both the 2016 and 2021 Censuses, the proportion of each has changed. The birthplaces with the highest growth were India, the Philippines, China, South Africa, Malaysia, and Bhutan. Migration patterns can affect the prevalence and distribution of genetic conditions in the community as ethnic diversity and disease risk profiles change. This has the potential to influence the number of and reasons for referral to GHWA over time.

Some consumers who identify as CaLD may be at higher risk of certain genetic conditions due to an increased prevalence of particular genetic changes or consanguinity (marriage between biological relatives) in their ethnic group. Moreover, the proportion of the Western Australian population born in a non-main English-speaking country is gradually becoming larger (17.5%) than the proportion born in a main English-speaking country (14.7%). This emphasises the growing need to address accessibility barriers affecting CaLD consumers and similarly for Aboriginal and Torres Strait Islander people.



[6] Australian Bureau of Statistics (2023) National, state and territory population, ABS Website, accessed 27/02/2024
[7] Office of Multicultural Interests (2024) Census 2021 Highlights: Western Australia's Changing Population and Cultural Diversity
[8] Australian Bureau of Statistics (2019) Estimates and Projections, Aboriginal and Torres Strait Islander Australians, ABS Website, accessed 26/02/2024
[9] Australian Bureau of Statistics (2022) Census of Population and Housing - Counts of Aboriginal and Torres Strait Islander Australians, ABS Website, accessed 27/02/2024

# Service activity overview

GHWA's recent service activity data is currently being analysed and a summary of this data will be included in the final Plan.

**Figure 7: A summary of GHWA's service activity from 2018 to 2022.** – To be included in the final Plan

# Service challenges

There are several issues which impact upon GHWA's ability to deliver timely and equitable clinical genomic speciality services. Some of these are system pressures resulting from the rapid advancement in genomic technologies and the consequent increasing clinical utilisation of genomic testing, which adds to the demand on GHWA's services. Whilst many of these challenges are outside of GHWA's control, it is necessary for these to be considered in planning for future service delivery. Additionally, there are some issues relating to the efficiency, accessibility, and sustainability of GHWA's services that would be beneficial for GHWA to address going forwards. These key service challenges are outlined below.

## Increasing complexity of genomic testing

- The complexity of genomic testing has expanded the work GHWA must undertake in pre-appointment preparation to ensure the most appropriate testing options are offered, the amount and type of information needed to be conveyed to consumers to enable informed consent for testing, and in the interpretation and explanation of (sometimes ambiguous) test results.
- As more disease-causing genes and gene variants are discovered, this will further increase demand for GHWA's expertise.
- There are limited criteria and guidelines available to support clinicians to select the most appropriate genomic test for patients, with complex disease presentations frequently requiring multiple approaches to confirm a genetic diagnosis.

## Extended turnaround times for genomic testing

- The capacity and capability of pathology services to meet the increasing demand for genomic testing influences the testing turnaround times and subsequently GHWA's timeliness of communicating results to consumers and referrers.
- Currently the wait time for genomic testing through WA's public pathology provider PathWest is variable depending on the test complexity and clinical urgency and there are no processes or systems to support the monitoring and communication of genomic test status with referrers. Furthermore, PathWest currently does not offer tests such as whole genome sequencing for certain genetic conditions.

## Limitations of funding for clinical genomic specialty services

- GHWA is primarily funded by activity-based funding (ABF), a national funding system used in Australian public hospitals so that hospitals receive funding based on the number and types of services they provide. GHWA claims ABF for outpatient services it delivers or leads (in the case of collaborative clinics).
- ABF should encompass all the costs associated with delivering a service. However, the ABF price allocated is based on retrospective costing data from across Australia and is not

sufficiently responsive to the fast-paced advancements in utility and complexity of genomic tests that are often associated with relatively significant costs.

- Without dedicated extra funding (except some funding through research programs), GHWA and PathWest have been hindered in facilitating consumer access to new genomic tests, including tests added to the Medicare Benefits Schedule[10]. This has the potential to lead to inequity of access to these tests for GHWA consumers.
- GHWA does not receive funding for certain activities it performs, such as inpatient consults, multidisciplinary or collaborative clinics where it is not the lead, and when it provides advice and training to other health professionals (e.g. on-call geneticist or genetic counsellor, MDT meetings, or case discussions with PathWest).

## Increasing support required by non-genomic specialists

- As the clinical utility of genomics increases, a growing number of non-genomic specialists are seeking expertise and support from GHWA around ordering and interpreting genomic tests, which has contributed to a rise in GHWA's workload for advising, counselling, and variant interpretation, which is often not adequately funded by ABF.
- No state-wide formal education program aimed at improving the genomic related capabilities of non-genomic specialists currently exists.

## Private clinical genomic specialty services

- Like other clinical healthcare specialties, private services play a role in the delivery of clinical genomic specialty services, although accessing private services can be a financial burden for some consumers and creates inequity in access, including to genomic testing.
- Additionally, although the scale of private clinical genomic specialty services in WA is growing, it remains relatively modest in size in relation to public services when compared to other healthcare specialties. Due to the small and highly specialised nature of the specialist genomic workforce, GHWA must take into consideration how a significant growth in private clinical genomic specialty services may impact GHWA's workforce.
- Furthermore, consumers attending a private genomics clinic may have at-risk family members requiring cascade counselling or testing who, for a number of reasons, may choose to go through the public health system. In these situations, they will be referred to GHWA, thus further increasing wait times for public clinical genomic specialty services (including genomic testing).

## Specialised genomic workforce shortages

- Training opportunities for both geneticists and genetic counsellors are constrained by the number of institutes offering certified programmes. The Royal Australasian College of

[10] Under MBS rules, public hospitals cannot claim Medicare rebates for pathology tests performed for public consumers as part of a hospital admission or outpatient clinic.

Physicians oversees all Australian geneticist training, while only 2 universities nationwide offer a master's degree in genetic counselling.

- Following training and certification, limited positions, opportunities in other states, and competition with the private and research sectors influence GHWA's ability to recruit additional staff and retain them.
- This has resulted in a gap between GHWA's current workforce numbers and recommended national benchmarks for geneticist and genetic counsellor positions[11].
- GHWA staff, in particular genetic counsellors, have limited workforce development opportunities (e.g. a lack of protected time and funding for participating in research and training activities) due to constraints within the current professional award. This limits genetic counsellors' ability to participate in professional development required for professional registration.

## Lack of formal agreements to work across Health Service Providers

- GHWA currently develops collaborations with specialists on an *ad hoc* basis as capacity allows, which potentially results in inequity in the delivery of clinical genomic specialty services across HSPs.
- Furthermore, there is a lack of formal agreement between GHWA and the HSPs as to how they deliver and fund collaborative clinics.

## Limited awareness of the service

- Some medical practitioners and staff working in primary and community care in WA are not aware of GHWA, the scope of service, the criteria for referral, or the ability to seek *ad hoc* advice from the service, which can prevent some consumers who would benefit from GHWA's services being referred.
- It also appears some consumers and carers do not fully understand the reason for their referral to GHWA and may not be informed of the services available to them upon acceptance of this referral, leading to reduced accessibility for these individuals.

## Difficulties with accessibility

- Some stakeholders feel that waiting times for appointments are unclear at the time of referral and can be too long. This can be challenging for consumers and carers, some of whom experience significant anxiety or uncertainty during this time, as well as referring clinicians, who may not receive communication about their patient until the completion of their appointment.

[11] Human Genetics Society of Australasia (February 2024) Clinical Genetic Services Framework (2024GL01). Available from: https://hgsa.org.au/Web/Consumer-resources/Policies-Position-Statements.aspx

- The location of GHWA's central hub at KEMH, a hospital with ageing infrastructure and limited space for expansion, and limitations on clinic spaces at other hospitals, impacts upon GHWA's ability to increase capacity to meet the growing demand for services.
- KEMH's clinic spaces are not appropriate to conduct all clinical examinations required and are not always suitable for adults who do not have a maternity-related health concern or consumers with accessibility requirements, such as those with physical or sensory impairments due to their genetic condition.
- The physical location of GHWA's services also poses a geographical barrier for consumers living in rural, regional, and remote areas for whom an in-person appointment is clinically required or preferred. This is particularly difficult for those living in regions not serviced by outreach clinics.
- People who identify as Aboriginal or CaLD experience an inequity of referrals and access to clinical genomic specialty services. These inequities are the result of several cultural and language barriers such as a lack of information and resources available in their first language, difficulties in awareness and understanding of how to access the service, stigmatisations of certain health issues, or insufficient provision of culturally informed care.

## Outdated clinical genomics database

- GHWA's current data entry and management system (KinTrak) is a legacy software no longer supported by contemporary information and communications technology (ICT), resulting in barriers to integration with other clinical data systems including the hospital patient database, webPAS.
- This hinders the ability to collect the required ABF data, leading to inefficiencies due to the need to double enter patient data into the hospital patient database webPAS and inaccuracies in data entry and reporting.
- It also inhibits GHWA's ability to accurately monitor its service activity, which is critical for measuring true service demand and informing future service planning.[12]

[12] Human Genetics Society of Australasia (February 2024) Clinical Genetic Services Framework (2024GL01). Available from: https://hgsa.org.au/Web/Consumer-resources/Policies-Position-Statements.aspx

# Future service model

This section outlines the optimal service model for GHWA in the future. It is acknowledged this ideal state will likely not be fully realised within the 5-year period covered by this Plan, and that achieving this ambitious vision will require ongoing commitment and support in the years following its implementation.

## Ensuring equitable, responsive, person- and family-centred services

As emphasised in the WA Genomics Strategy, person- and family-centredness is a central priority for all genomic services and will remain at the core of any future service developments for GHWA. Going forwards, GHWA will continue to provide a person- and family-centred service throughout WA for the diagnosis, management, and support of individuals with or suspected with genetic conditions, as well as their families and carers. Furthermore, GHWA will work with existing and new partners to promote and support the delivery of genomic healthcare in WA in a person and family-centred manner.

GHWA's current operational model, encompassing centralised services with networked outreach clinics, will be enhanced to facilitate Western Australians to have equitable access to services closer to where they live. This will require improved service efficiency, enhanced capacity, and the exploration of innovative workforce and service models to meet increasing demand, particularly in rural and remote areas. A mixed mode of service delivery, including face-to-face consultation and virtual or digital health approaches to care, will ensure GHWA is responsive to consumer preferences and accessibility requirements in line with their clinical needs and will provide further opportunities to minimise the burden of travel for both consumers and GHWA staff. In partnership with stakeholders, GHWA will also develop innovative approaches to service delivery which consider how the diverse needs of consumers across various ethnic, social, and cultural groups can be met to help address existing barriers to access. GHWA will also partner with providers within hospital, primary, social, and community healthcare services to ensure consumers receive appropriate follow up and support across the care continuum.

## Working at the highest scope of practice

GHWA will continue to offer clinical genomic specialty services to all Western Australians and its role will evolve to focus on optimising care for consumers, carers, and families with complicated symptoms and/or who require a greater level of support. GHWA will prioritise the diagnosis and management of individuals and families with complex, multisystem, and rare genetic conditions, including inherited cancers. This will involve collaborating with stakeholders to develop clearly defined referral pathways to ensure consumers with complex needs are directed to GHWA and/or other appropriate clinical services. These pathways will facilitate timely referrals to GHWA for consumers who most need GHWA's specialty services, as well as family members who are eligible for cascade screening and counselling.

In the long term and as capacity allows, GHWA will explore opportunities to coordinate the ongoing care and management of consumers with rare genetic disorders or undiagnosed conditions where clinical expertise and management is not available through other services. This will include facilitating access to clinical trials and emerging therapies for these

consumers. In addition, GHWA will drive care coordination and health surveillance for complex, multisystem genetic disorders, for which a priority will be placed on adults with a genetic predisposition to cancer (with management and surveillance of children with inherited cancer predisposition syndromes to be led by PCH).

## Supporting the implementation of genomics across WA

The rapid advancement in genomic knowledge and technology has contributed to the broader implementation of genomics across the Western Australian health system as clinicians in other specialties become more aware of the advantages of utilising genomics to inform precision medicine approaches. Whilst this can provide consumers with timelier access to genomic testing by a specialist they are already familiar with, there are recognised challenges to the delivery of genomic medicine by non-genomic specialists. There is a pertinent need for the Western Australian health system to provide education, training, and development opportunities along with appropriate policies and clinical pathways to ensure genomic healthcare is delivered by non-genomic specialists in a safe, person- and family-centred manner where consumer autonomy and informed consent are upheld. GHWA's expertise will help to inform this work, which will take a stepwise and tailored approach focusing on clinical areas with emerging utility and application of genomics. It is anticipated that GHWA's involvement would be stratified based on genomic complexity, patient numbers and impact to consumers and families and would complement other measures introduced by the Department of Health to guide the safe adoption of genomics into the Western Australian health system as part of the implementation of the WA Genomics Strategy.

Given the value of collaborations for both consumers and clinicians in genomic health care delivery, GHWA's role will include increased participation in joint clinics and MDT meetings. In addition to this, GHWA will collaborate with stakeholders to co-develop clinical guidelines or decision aids which will support a person- and family-centred model of genomic healthcare delivery while reducing the time to access genomic testing, diagnoses and facilitating ongoing patient management.

GHWA will also support the Department of Health, HSPs, and other relevant organisations in training and educating health professionals in other clinical specialities, including primary care, to develop their knowledge and skills to directly request appropriate genomic testing within their scope of practice and understand how results can impact on patient care and their family. It is recognised that these efforts will vary depending on the unique needs of different non-genomic specialties and should take into consideration existing genomic knowledge, models of care, and specialist and consumer preferences. It will also be necessary to gain input and support from other services such as PathWest and utilise clinical and genomic testing data to identify the clinical areas of need for GHWA's support.

The rapid pace of development in genomic knowledge means that research is recognised as a fundamental part of clinical genomic service delivery, to enhance the understanding, prevention, and treatment of genetic conditions. GHWA will play a key role in supporting the timely translation of genomic research into clinical care by participating in local, national, and international research programs, as well as contributing to the development of evidence-based guidelines and innovative service design.

Figure 8 below provides a conceptual diagram of the future role described here.

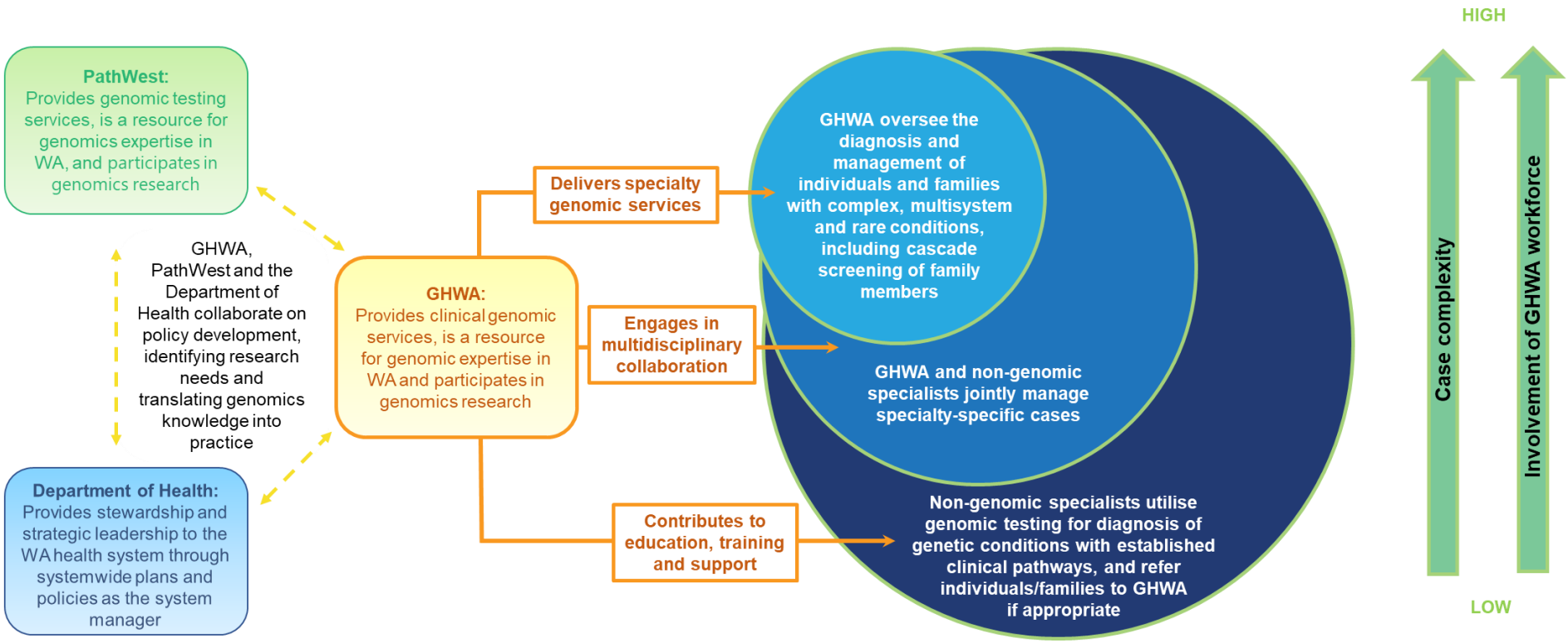


**Figure 8: A conceptual framework showing GHWA's role in the future state of genomic healthcare delivery in WA.**

# Service directions

Four service directions have been outlined below to provide an overview of the key objectives and actions to guide the delivery of GHWA's services over the next 5 years:

1. Building capacity, capability, and sustainability to deliver high-value care
2. Increasing awareness, responsiveness, and accessibility
3. Enhancing integration and care coordination
4. Fostering excellence in genomic health care across WA

Person- and family-centred care is essential to the delivery of safe, high-quality care, and is a central priority underlying all service directions for GHWA (see Figure 9).

Engagement and partnership with consumers and carers in the planning, delivery, and evaluation of GHWA's services is paramount, and should be prioritised across all service directions to ensure that value-based, person- and family-centred care is continued into the future.

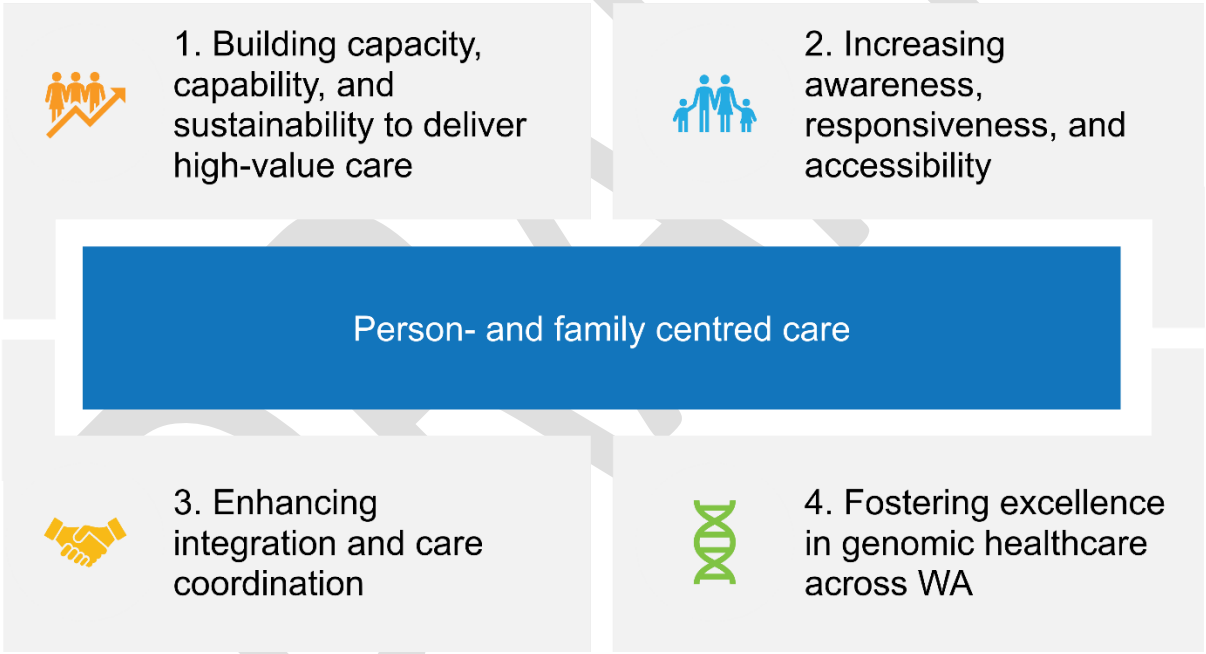


**Figure 9: GHWA's service directions for the next 5 years.**

## 1. Building capacity, capability, and sustainability to deliver high-value care

High-value health care aims to reduce system waste, eliminate unwarranted clinical variation, and direct resources to areas of greatest need. This is particularly important to realising an integrated genomic healthcare environment where consumers, carers, and family members receive safe, high-quality, and person- and family-centred care based on the best available evidence.

Resources, workforce, and processes are fundamental building blocks to efficient health service delivery and are crucial elements to ensure provision of sustainable, high-quality, safe, and person- and family-centred clinical genomic specialty services into the future. Dedicated planning, leadership and investment will be required to support the design and implementation of effective, sustainable, and innovative service models.

Expanding service capacity will be necessary and this will be partly addressed by GHWA in the immediate term by optimising operational efficiency (including through streamlining processes, utilising digital tools, and exploring alternative workforce models) and implementing innovative models of service delivery. However, in optimising service processes, the experience of consumers, carers and family members will remain a key priority, and GHWA should continue to ensure that they receive high-quality, person- and family-centred care amidst operational changes.

GHWA will undertake regular service and workforce planning, which will be underpinned by strengthened data collection systems that enable ongoing service monitoring, and evaluation and horizon scanning. Service improvements will be designed and implemented in collaboration with stakeholders to ensure that these are aligned to best practice and meet the needs of consumers and families, the health workforce, and the Western Australian health system. This will include drawing on service-level data to inform the development of new evidence-based models of care and to drive consistency in genomic service delivery across the Western Australian health system.

Achieving the objectives in this service direction will support the ongoing delivery of timely, equitable and effective person- and family-centred clinical genomic specialty services for Western Australians. It will also allow GHWA to operate at the top of their scope of practice, implement key priorities arising from this service plan, and utilise their expertise to explore and undertake new key roles within the Western Australian health system to help optimise the provision of clinical genomic specialty services in WA into the future. Ultimately, new resources will be required to continue expanding the capacity, capability, and sustainability of GHWA to achieve this vision. These additional resources will be sourced through normal budgetary processes, supported by high-quality service data and evidence-based service planning.

### Objectives

1. Review and streamline internal operating models and pathways to improve efficiency and consistency of service delivery *(Actions 1-5)*.
2. Explore and adopt innovations in service delivery (including digital tools where appropriate) to optimise processes and increase productivity *(Actions 6-7)*.

3. Develop a sustainable genomic specialist workforce with the capacity and capability to deliver best-practice, safe, and effective clinical genomic specialty services across WA *(Actions 8-10)*.
4. Engage in evidence-based service planning, monitoring, and evaluation in collaboration with stakeholders to ensure GHWA continues to provide services which meet the needs of the Western Australian population *(Actions 11-13)*.

### *Actions*

1. Complete the implementation of a new clinical database and establish consistent processes for data recording to improve service flow, data control, and reporting efficiency and accuracy.
2. Develop, implement and maintain standard operating procedures, guidelines, and protocols to reduce service variation.
3. In collaboration with stakeholders, review and optimise the consumer pathway through GHWA, including refining communication around referral procedures and pathways.
4. Develop and regularly review WA health system Referral Access Criteria based on evidence and stakeholder engagement to standardise the referral process by improving communication between referrers and GHWA, consistency in referral acceptance and triage practices, and quality of referrals.
5. Explore the optimal subspecialty model for GHWA to ensure it best reflects the evolution of genomics knowledge and demand, such as in areas of adult cardiac and renal genetics.
6. Explore and pilot innovative methods to streamline the collection of family history and medical information, such as digital consumer-driven forms.
7. Implement digital mechanisms to improve communication and information-sharing with referrers, including secure messaging systems and linking of digital records to ensure accessibility of clinical letters.
8. Utilise service data and clinical frameworks to inform new workforce models to improve service efficiency, capacity, and sustainability, including identifying additional staffing needs (e.g. additional clinical geneticist and genetic counsellor trainee positions, allied health workers/nurses/psychologists trained in genomics, intake and data entry assistants, or administration staff).
9. Increase staff access to continuing professional development and networking opportunities to ensure staff knowledge and skills meet the evolving needs of GHWA.
10. Collaborate with stakeholders, such as the Department of Health and educational institutions, to develop education, training, attraction, and retention programs for the relevant specialised genomics workforce in WA.
11. Establish key performance indicators for GHWA in collaboration with the Department of Health to facilitate regular service monitoring, evaluation, and quality improvement.
12. Pilot the prospective collection of service quality data (e.g. patient-reported experience and outcome measures) to understand and optimise service delivery.
13. Work with the Department of Health to explore and advocate for sustainable funding models for specialised genomic services.

## 2. Increasing awareness, responsiveness, and accessibility

Despite its increasing utilisation in the health system, it is recognised that the awareness and understanding of clinical genomics varies considerably across the community and healthcare professionals. This includes knowledge of genetic risk factors and pathways to accessing clinical genomic specialty services, representing a key barrier to the access to and uptake of genomic health care. GHWA will ensure that information provided to stakeholders is clear, comprehensive, and accessible to help promote and increase awareness of GHWA, the services that it provides, and the referral pathways into the service. Where appropriate, this information will be tailored to and developed in collaboration with relevant stakeholders to ensure that information is fit-for-purpose and disseminated widely and effectively. This will also improve the ability and confidence of stakeholders to identify those who have or are at risk of having a genetic condition, and ensure they are able to access clinical genomic specialty services as needed.

Person- and family-centred care involves working with consumers, carers, and their families to undertake shared decision-making and care planning. Quintessential to this is clear, effective communication to ensure that consumers have a strong understanding of genomic concepts, the reasons for their referral, and what will occur during their appointments. In addition, person- and family-centred care considers and respects the preferences, culture, and beliefs of consumers, and acknowledges the familial implications of genomics. GHWA will continue to provide high-quality, person- and family-centred care to consumers, carers, and their family members that is responsive to their needs by improving communication, exploring person- and family-centred models of care and utilising digital tools to improve consumer access and experiences. This will be undertaken through purposeful and responsive stakeholder engagement to help understand the needs and preferences of consumers, carers, and family members, and develop strategies and improved models of care to address these.

Partnerships with community services are particularly important to understand and address the diverse needs of the wider community, and specifically communities that experience inequity of access. GHWA will focus on refining, developing, and implementing models of care, strategies, and pathways to increase equity of access for populations that experience heightened barriers to receiving genomic health care and which require additional support needs. This will provide GHWA with a strong foundation to explore and expand its strategies to increase access to clinical genomic specialty services for all Western Australians more broadly into the future.

Overall, achieving these objectives will continue to enable consumers, carers, and their family members to be genuine partners in the decision-making and planning of their care, and facilitate the equitable, timely and appropriate provision of clinical genomic specialty services in WA.

### Objectives

1. Improve the quality, availability, and dissemination of information designed to increase awareness amongst stakeholders of GHWA and the services it provides throughout WA and ensure that consumers with the greatest need can access GHWA's services *(Actions 1-3)*.
2. Increase engagement with stakeholders including consumers, carers, community groups, and health and social care providers to develop strategies to enhance access,

care, and support for populations that experience heightened barriers to accessing clinical genomic specialty services *(Actions 4-6)*.

3. Review, develop, and implement strategies, pathways, and innovative models of care in partnership with stakeholders to continue being responsive to the diverse needs of consumers, carers, and family members *(Actions 7-8)*.

### *Actions*

1. Develop a single website in consultation with stakeholders to best support their information needs and improve awareness of GHWA's services, including by providing:
    a. Information in different formats (e.g. Easy English, graphics and videos).
    b. Information translated into languages other than English.
    c. Additional details of services provided (e.g. clinic locations and types, referral triage principles or categories, conditions not seen and alternative care pathways for these, and indicative waiting times for appointments within each GHWA subspecialty).
2. Develop and implement a communication and/or engagement plan to promote GHWA to consumers, primary care, and other non-genomic service providers, and increase awareness and understanding of the services provided. This plan should prioritise stakeholders and consumers who historically have not been reached or experience barriers to access.
3. Contribute to, develop, and promote education material and guidelines for primary care and other non-genomic specialists to enhance and support referrals to GHWA, including materials which supplement Referral Access Criteria, build knowledge about how to recognise consumers likely to have a genetic condition and how to gather information necessary for referral to GHWA.
4. Develop strategies to improve the provision of culturally appropriate care and equity of access for Aboriginal and CaLD consumers and carers, such as:
    a. In partnership with consumers, community services, local government agencies, and multicultural health service organisations, develop service models and pathways to improve accessibility for these populations, using co-design where appropriate and feasible.
    b. In collaboration with the Department of Health, investigate avenues to upskill relevant support staff (e.g. Aboriginal Liaison Officers and interpreters) in genomic concepts.
    c. Recruit staff who are of CaLD or Aboriginal background and providing all staff with cultural awareness training.
5. Informed by service utilisation data and stakeholder consultations, explore requirements and opportunities to provide additional outreach clinics in rural and regional areas to increase accessibility for underserviced populations.
6. In partnership with consumers and families, explore and pilot person- and family-centred models for service delivery to enable consumers to be active partners in decision-making around their care, such as:
    a. Mechanisms to keep consumers informed of the status of their genomic testing.

b. Taking into consideration consumers' preferred times and format (e.g. telehealth or face-to-face) where possible when scheduling appointments and the delivery of genomic testing results.
c. Accessible educational resources (e.g. fact sheets or videos on genomic testing and genetic conditions in multiple languages) and digital consenting for genomic testing to increase consumer genomic literacy, allow for more informed consent, and empower consumers to participate in clinical decision-making.
d. Development of visual, Easy English, and/or translated summaries for consumers following their appointments to facilitate understanding of appointment outcomes.

7. Work with WNHS and consumers to improve and redesign GHWA infrastructure to better meet rising demand for services and consumer needs such as cultural and physical accessibility.

## 3. Enhancing integration and care coordination

Integrated care involves the provision of seamless, effective, and efficient health care that reflects the whole of a person's health needs in partnership with consumers, carers, and family members and other health service providers. This is particularly important to consider in clinical genomics, which is a complex clinical area that spans nearly every medical discipline and has an extensive range of care and management implications (both short- and long-term for the patient, as well as potential implications for family members). Genomic specialists have expertise in providing diagnosis, counselling, and management advice to consumers, carers, and family members at risk of or affected by an inherited condition, but the ongoing management and support of the patient's health and social needs can involve many other services and health professionals. Providing care that minimises duplication and achieves shared outcomes will be reliant on the development of purposeful partnerships that improve coordination, communication, and connectivity between GHWA and service providers across community health, social and primary care, and hospital services. This will ensure consumers receive the right care, at the right time, and in the right place.

GHWA will extend the emotional and psychosocial support currently provided to consumers and develop strategies to enhance continuity of timely and coordinated services across the care continuum. This includes empowering consumers to access support services, ensuring that clear, comprehensive, and accessible information is provided to referring clinicians about ongoing management, referring patients to other medical and psychological services when required, and developing strong partnerships with professional and community organisations. GHWA will also explore opportunities to promote coordinated care for consumers, carers, and family members who are currently not being adequately served in the Western Australian health system (e.g. those with rare diseases) through potential care coordination roles and joint clinics with other health professionals, ensuring that these additional collaborations are formally established based on evidence and need, and are sustainably implemented into the future.

### Objectives

1. Refine and develop strategies to improve continuity of care for consumers and carers in partnership with stakeholders, including ongoing management, disease surveillance and care coordination *(Actions 1-6)*.
2. In partnership with HSPs, review, maintain and expand clinical pathways and arrangements that formally recognise GHWA's role in the delivery of services throughout the state. This will embed access to specialised genomics services and advice into non-genomic clinical services (such as via multidisciplinary teams and outreach/joint clinics) and ensure all Western Australians have timely access to appropriate and coordinated genomic health care *(Actions 7-10)*.

#### *Actions*

1. Expand GHWA's involvement in evidence-based screening for and management of Tier 1 genomic applications[13], including:

[13] US Centres for Disease Control and Prevention (March 2014). Tier 1 Genomics Applications and their Importance to Public Health. Available from: https://archive.cdc.gov/#/details?url=https://www.cdc.gov/genomics/implementation/toolkit/tier1.htm

a. Enhance and maintain the Familial Cancer Registry and formally embed an adult familial cancer surveillance clinic within GHWA to improve the identification, surveillance, and treatment of individuals and families with familial cancer syndromes for which surveillance is currently not available.
b. Explore avenues for GHWA to support the implementation of pathways to improve the identification, counselling, and management of individuals with familial hypercholesterolaemia and the provision of cascade screening and counselling for their family members.

2. Continue to work with the Department of Health and relevant HSPs to contribute to efforts to increase accessibility of relevant genomic information for consumers and clinicians to support ongoing patient management and continuity of care.
3. Develop and implement standardised processes for consumers to be directed to support services, including peer support groups and psychological support.
4. Work with PathWest to investigate options for re-analysis of inconclusive genomic testing results.
5. Work with stakeholders to pilot innovative models of care (e.g. co-consultation with primary care providers) to improve continuity of care for consumers, carers, and their family members.
6. Scope the feasibility of an expanded role for GHWA in coordinating care, managing ongoing care and complex psychosocial support needs, and providing disease surveillance for consumers with unmet needs, including those:
    a. With an undiagnosed condition.
    b. With rare, complex multisystem conditions (e.g. familial cancer syndromes and rare diseases without a clear “home” medical specialty).
    c. Transitioning from paediatric to adult care.
7. Evaluate the clinical, economic, and social impact of existing joint clinics and other collaborative service delivery models.
8. Work with HSPs to formalise arrangements for services provided by GHWA to other Health Service Providers.
9. Explore sustainable and equitable ways to expand GHWA’s involvement in joint clinics and multidisciplinary team meetings (e.g. based on clinical evidence, demand, and service capacity and capability).
10. Work with the Department of Health and PathWest to identify the clinical areas of need for future clinical genomic specialty services by GHWA (e.g. multidisciplinary work, supporting non-genomic specialists, or assisting with referrals to GHWA) by examining current clinical service and testing data.

## 4. Fostering excellence in genomic health care across WA

As the sole provider of public clinical genomic specialty services, GHWA is uniquely positioned to support innovative, high-value patient- and family-centred genomic health care by sharing their specialised genomics expertise across the WA health system. GHWA will partner with the Department of Health, PathWest, and other service providers to develop a strategic and stepwise approach to improve the integration of genomics into clinical practice of a range of medical specialities. A flexible approach will be required with different pathways needed for clinical specialities dependent on the existing clinical pathways, the conditions their patients have, workforce capability, and specialists' awareness and knowledge of genomics.

A key enabler to providing patient- and family-centred services is building partnerships between genomic and non-genomic specialists to enhance knowledge and confidence of clinicians and ensure that consumers, carers, and family members continue to receive appropriate care. This will include expanding GHWA's involvement in joint clinics and multidisciplinary team meetings and exploring digital tools and other innovative ways to increase the accessibility and provision of advice to non-genomic specialists to support appropriate genomic testing requests, referrals to clinical genomic specialty services, and communication to consumers about the implications of genomic information. GHWA will also work with the Department of Health, PathWest, and other HSPs in the design and delivery of education and training programs, best practice guidelines and other resources aimed at improving the genomic-related capabilities of the multi-professional healthcare workforce across all service levels. This may require additional funding to support the procurement and development of educational resources and dedicated staff time for training activities.

Research and innovation are fundamental components in evidence-based service delivery. This is particularly important to consider in the dynamic environment of clinical genomics, with newer, faster diagnostic technologies and emerging range of gene therapies meaning that Western Australians can gain greater access to timely genetic diagnoses, more personalised care, and better outcomes. GHWA will continue to be involved in, utilise, and explore research, innovation, and digital technologies, and together with consumers, clinicians, laboratory scientists, academics, and policy makers, translate genomic research and innovation into clinical practice. This may require investment in research infrastructure, resources, and staff time to better enable GHWA to lead and participate in clinical research activities.

Achieving these objectives will help to ensure the optimal integration of genomic knowledge into the Western Australian health system and facilitate the delivery of high-value genomic health care which benefits all Western Australians.

### Objectives

1. Collaborate with partners and stakeholders to share best clinical practice, develop clinical and policy guidance, and set direction for future genomic healthcare services *(Actions 1-3)*.
2. Build education and training capacity within GHWA to support the delivery of genomics in non-genomic clinical services by expanding the provision of advice to non-genomic specialists and providing input on education and training programs for upskilling health professionals in genomics *(Action 4-6)*.

3. Participate in and lead research and translation projects to advance the adoption of new genomic technologies and knowledge into clinical practice *(Actions 7-10)*.

### *Actions*

1. Work with the Department of Health and PathWest to explore the most effective and suitable pathways for genomic testing which will ensure appropriate and timely access to clinical genomic specialty services for consumers.
2. Undertake horizon scanning across medical specialties for genomic applications that may have clinical utility in the short- and medium-term.
3. Contribute advice and expertise to the Department of Health to inform health genomics policy and guidelines.
4. Investigate options for sustainable dedicated funding to support GHWA's participation in the development and delivery of genomics education and training activities for consumers and health professionals.
5. Explore digital avenues to provide advice to non-genomic specialists, including enhancing access or linkage to specialty-specific clinical geneticists or genetic counsellors.
6. Provide input into and support education strategies and training models to upskill non-genomic specialists and enable delivery of safe person- and family-centred genomic healthcare services in WA in partnership with the Department of Health.
7. Explore opportunities to invest in and grow research capabilities within GHWA to enable greater involvement in clinical research.
8. Increase participation in the development of evidence-based models of care.
9. Lead and participate in local, national, and international research translation and quality improvement projects.
10. Explore opportunities to increase consumer access to clinical trials and innovative treatments, including those for novel genetic therapies and other precision medicines.

# Future considerations

## Implementation

The Plan will be implemented in a phased approach, with as many actions implemented as possible over the 5-year period depending on the availability of resources and the strategic priorities of the NMHS and the Western Australian health system more broadly. To achieve this, it will be necessary for GHWA to develop an implementation approach to prioritise the actions for completion and define measures to assess progress towards realising the objectives. Implementation will occur in a phased approach with actions allocated in stages across the 5-year period. Building on the co-design approach employed in the development of the Plan, implementation of the actions will be led by GHWA, and undertaken in consultation with key partners including consumers, other healthcare providers, the Department of Health, and the WA Genomics Strategy Implementation Committee. This will ensure the approach best reflects the needs of all stakeholders and aligns with the implementation of the WA Genomics Strategy across the Western Australian health system.

## Enablers of success

There are several key enablers that will be necessary to successfully implement this service plan. This includes the enablers outlined in the WA Genomic Strategy such as sustainable funding of genomic services; senior leadership and support; accountability, roles and responsibilities; and meaningful partnership and collaboration.

The WA Genomics Strategy highlights the vital role played by senior leadership, and the need for clear roles and responsibilities for all stakeholders to ensure accountability for genomic healthcare. As such, GHWA will need to identify individuals who can guide the adoption of innovative service models or care pathways and lead behaviour change across the system, as well as work closely with senior leadership at the executive level across HSPs to ensure effective implementation and monitoring of the Plan.

As touched on above, meaningful partnerships and collaboration with all stakeholders at the local, national, and international level will enable GHWA to achieve the objectives of this plan. While additional resources are likely to be required to establish and build meaningful partnerships, this will ultimately help to expand service capacity and capability through leveraging efforts, identifying synergies, and reducing duplication over the duration of the Plan's implementation and beyond. As a priority, GHWA will explore the ideal mechanisms to embed consumer and carer voices by considering opportunities to leverage existing engagement bodies and available resources.

As identified in the WA Genomics Strategy, the key areas of genomic workforce, infrastructure and data management would benefit greatly from upfront investment. Such focused investment for GHWA will provide greater opportunities for improvement, growth, and expansion, all necessary to realise the ideal approach to future clinical genomic service delivery in WA.

GHWA will need a skilled, agile, and diverse workforce that is committed to delivering high-quality clinical genomic specialty services and able to embrace new ways of working. GHWA will also benefit from contemporary and fit-for-purpose ICT which can facilitate seamless

collection and sharing of relevant information to enhance continuity of care. Finally, appropriate infrastructure that enables GHWA to meet the increasing demand for services and the physical, cultural, and psychosocial needs of staff and consumers will be key to ensuring high quality service delivery into the future.

## Review and evaluation

It is anticipated that some actions within this plan may require modification over time in response to the rapidly changing genomics environment in WA. Furthermore, it is noted that the Plan includes an ambitious range of actions to implement in the timeframe allocated. As such, any actions unable to be completed within the 5-year timeframe will be carried over and pursued as part of the review and evaluation process. Regular review of progress against the objectives will be undertaken by GHWA in conjunction with NMHS Clinical Planning and reported via the usual clinical governance pathway. The Plan will be evaluated by NMHS Clinical Planning following implementation to assess the impact of the plan on service delivery and inform the development of future GHWA service plans.

# Glossary

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| **ABF** | activity-based funding |
| **CAHS** | Child and Adolescent Health Service |
| **CaLD** | culturally and linguistically diverse |
| **cascade testing** | testing for changes to an individual's genetic information previously identified in a biological relative. Includes predictive, parental, and carrier testing |
| **consumer** | a user of health services, e.g. patient or carer |
| **clinical genomic specialty services** | diagnosis, genetic counselling, and care and management of individuals and families with, suspected of, or at risk of a genetic condition provided by genomic specialists |
| **cytogenetic analyses** | study of the structure and properties of chromosomes, encompassing karyotyping, fluorescent in situ hybridisation, microarray, and chromosomal instability studies |
| **diagnostic testing** | testing to identify genetic changes in an individual that are symptom causative. Results can confirm a suspected diagnosis or exclude a differential diagnosis |
| **DNA** | deoxyribonucleic acid, which is the molecule that carries the genetic information necessary for the development and function of an organism, e.g. a human |
| **DNA sequencing** | testing to identify changes in an individual's genetic information |
| **EMHS** | East Metropolitan Health Service |

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| **exome** | The approximately 1.5-2% of the genome that codes for proteins |
| **FCP** | Familial Cancer Program; one of GHWA's subspecialties |
| **FSH** | Fiona Stanley Hospital |
| **FTE** | full-time equivalent |
| **gene** | the functional components of the DNA sequence that contain the operational instructions for all cells in the human body |
| **genetic counsellor** | genetic counsellor |
| **geneticist** | clinical geneticist |
| **genetic condition** | a disease arising from change(s) to an individual's DNA code. These can be germline (present in all cells at birth) or somatic (arising in individual cells throughout one's life) |
| **genetics** | the study of the functions and composition of single genes |
| **genome** | all the DNA code within an individual |
| **genomics** | the study of single, multiple, all genes, or all the DNA code in an individual and how they interact with each other and the environment |
| **genomic healthcare/ medicine** | health care informed by genomic knowledge. Includes clinical genomic specialty services and other precision medicine approaches delivered by non-genomic specialists |

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| **genomic specialists** | health professionals formally trained in genomics, e.g. clinical geneticist, genetic counsellor |
| **germline testing** | testing for inherited changes in an individual's genetic information (e.g. those they are born with) |
| **GHWA** | Genetic Health Western Australia; the sole public provider of clinical genomic specialty services in WA |
| **GP** | general practitioner |
| **GPS** | Genetic Paediatric Services; one of GHWA's subspecialties |
| **HCC** | Health Consumers' Council WA |
| **HGSA** | Human Genetics Society of Australasia |
| **high-value care** | health care which produces the greatest benefits for the lowest cost |
| **HSPs** | Health Service Providers |
| **ICT** | information and communications technology |
| **KEMH** | King Edward Memorial Hospital |
| **MBS** | Medicare Benefits Schedule |

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| **NMHS** | North Metropolitan Health Service |
| **non-genomic specialist/workforce** | health professionals who have not received formal genomics specialty training, e.g. GP, paediatrician, nurse, social worker |
| **OGGS** | Obstetrics and General Genetic Services; one of GHWA's subspecialties |
| **OPHG** | Office of Population Health Genomics |
| **PathWest** | PathWest Laboratory Medicine WA; the sole public provider of pathology and genomic testing in WA |
| **PCH** | Perth Children's Hospital |
| **people with learned experience** | those who have experience treating people with a genetic condition or referring people to GHWA, e.g. clinicians |
| **people with lived experience** | those who live with or care for someone with a genetic condition who has attended GHWA, e.g. consumer, carer |
| **predictive testing** | a type of cascade testing in an at-risk but currently unaffected individual for a genetic change that has already been identified in a blood relative |
| **primary care representative** | GPs, nurses, and other health professionals that provide health care in a primary care setting |
| **reproductive carrier testing** | testing to determine if prospective parent(s) carry genetic changes that increase their risk of having a child with a genetic condition |

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| **RPH** | Royal Perth Hospital |
| **SCGH** | Sir Charles Gairdner Hospital |
| **SMHS** | South Metropolitan Health Service |
| **somatic testing** | testing for non-inherited genetic changes acquired within a confined body of cells or tissues in an individual (also known as tumour testing in cells giving rise to a cancer) |
| **The Act** | The *Health Services Act 2016* |
| **The Plan** | Genetic Health Western Australia Service plan 2024-2029 |
| **VUS** | variant of uncertain significance |
| **WA** | Western Australia |
| **WA Genomics Strategy** | *WA Genomics Strategy 2022-2032: Towards precision medicine and precision public health* |
| **WACHS** | WA Country Health Service |
| **WNHS** | Women and Newborn Health Service |

# Appendix 1: Co-design approach

## What is co-design?

Co-design is a deliberate and collaborative approach to designing policies, services and research done in partnership with consumers and the community to ensure that results effectively address the needs of end-users[14]. Co-design places equal value in the input from consumers as other stakeholders, seeking to actively learn from their experiences to identify issues, define problems and design a solution. Rather than other engagement approaches where feedback from end-users is sought after the development of projects, co-design involves them at the outset of a project. It is widely recognised that co-designed services are more likely to meet the needs of end-users, improve services and generate more innovative ideas[15,16].

## The co-design approach for the Plan

The approach to co-design adopted for the development of the Plan brought together people with lived experience of GHWA, representatives from community organisations, clinicians, and other health staff from the beginning to shape and provide input on the project planning, design and delivery of the stakeholder engagement activities, interpretation of findings from the stakeholder engagement activities and the drafting of the Plan. Two project oversight groups were established with representatives from the range of GHWA's stakeholders, including a GHWA consumer and GHWA carer representative, and both were co-chaired by a lived experience consultant. This enabled a discrete co-design team to be formed, with a balanced representation of people with lived experience of GHWA and people with learned experience of GHWA to advise on the co-design of the Plan.

### Project oversight

#### Co-Design Team

The GHWA Service plan Co-Design Team (Co-Design Team) was established to guide the codesign and stakeholder engagement approach. The Co-Design Team comprised of a balanced representation of people with lived and learned experience, including:

- 2 consumer representatives (one patient and one carer)
- 2 representatives from community organisations
- 1 representative from GHWA
- 1 lived experience consultant (co-chair)
- 1 Department of Health Project Manager representative (co-chair)
- 1 Department of Health Project Team member

The Co-Design Team met 7 times from March to December 2023 to discuss and collaborate on the stakeholder engagement plan, stakeholder engagement activities and the service planning

[14] Blomkamp, E (2018) The Promise of Co-Design for Public Policy. *Australian Journal of Public Administration*, 77(4), 729-743.
[15] McKercher (2020) *Beyond sticky notes: Co-design for real: Mindsets, methods and movements*. Sydney, Australia: Beyond Sticky Notes.
[16] Steen, M, Manschot, M, & De Konig, N (2011) Benefits of Co-design in Service Design Projects. *International Journal of Design*, 5(2), 53-60.

process. The Co-Design Team was guided by the *Working with Consumers and Carers Toolkit* (Department of Health) guiding principles:

1. Accessible and inclusive
2. Respectful and safe
3. Authentic
4. Clear communication and transparency
5. Purposeful
6. Committed and accountable

To note: an additional Co-Design Team meeting is planned for June 2024.

### Working Group

The role of the GHWA Service Plan Working Group was to provide strategic guidance and expertise on clinical planning and the provision of genomic health care. The Working Group included all the members of the Co-Design Team in addition to members representing:

- Primary care referrer to GHWA
- Primary care liaison
- Non-genomic medical specialist referring to GHWA
- Non-genomic medical specialist not currently referring to GHWA
- Aboriginal Community Controlled Health Service
- Genomic testing provision
- Clinical planning
- WACHS

The Working Group was also co-chaired by a lived experience consultant.

The Working Group met in April and December 2023 to discuss the stakeholder engagement plan and outcomes from the stakeholder engagement activities. To note: an additional Working Group meeting is planned for June 2024.

## Stakeholder engagement activities

A total of 8 distinct stakeholder engagement activities were conducted by the Health Consumers' Council of WA (HCC) and the Office of Population Health Genomics (OPHG) to inform the Plan. The aim of these activities was to understand the experience and perspectives of stakeholders on the current and future service delivery of GHWA. Each activity was tailored to the stakeholder group targeted and covered a broad range of topics. The outcomes from all activities were discussed with the Co-Design Team and Working Group in December 2023.

### Community survey

A community survey was hosted from July to August 2023 by the HCC. The survey was completed by 252 consumers and carers from GHWA, with representation from the 3 subspecialities currently offered by GHWA. This included consumers who self-identified as:

- Aboriginal and/or Torres Strait Islander (3%)
- CaLD (10%)
- Currently living in a rural, regional or remote area (15%)
- Living with and/or caring for someone with a disability (26%)

### Lived experience focus groups and interviews

Three focus groups and 9 interviews were conducted by HCC with 17 consumers and carers from August and September 2023, including:

- 9 consumers that identified as CaLD
- 2 consumers that identified as Aboriginal and/or Torres Strait Islander
- 5 consumers that identified as living in a rural, regional or remote area

These consumers were evenly split across the subspecialities at GHWA.

### Clinician and Support Service survey

The Clinician and Support Service survey was hosted from June to August 2023 by the OPHG for primary care specialists, other medical specialists, and support service staff. This survey was completed by 26 clinicians, including 7 GPs and 19 non-genomic medical specialists. No support service staff completed the survey.

### GHWA staff survey

A survey for GHWA staff was internally hosted by the OPHG in August 2023. This survey was completed by 18 staff members in various roles including clinic coordination, data management, clinical geneticists, and genetic counsellors.

### GHWA staff focus groups

Three focus groups with GHWA staff were held in August 2023, with 25 staff members participating. This included staff across a range of roles, including genetic counsellors, clinical geneticists, administration staff, data management and clinic coordination staff.

### Primary care focus group

One focus group for primary care providers run by an external facilitator was held in August 2023. It was attended by 2 GPs practicing in metropolitan Perth.

### Clinician interviews

Eleven interviews were held with 13 healthcare professionals throughout August and November 2023. Interviewees included 4 non-genomic specialists participating in multidisciplinary clinics with GHWA, 6 non-genomic specialists who refer to GHWA, one GP who refers to GHWA and 2 staff members from a community health service. Specialists interviewed were from a range of clinical disciplines and were employed at various HSPs within the Western Australian health system.

### Multistakeholder workshop

A multistakeholder workshop was held on 12 October 2023, with 40 participants attending including:

- 15 consumers and carers who have attended an appointment with GHWA
- 4 GPs
- 10 other medical specialists
- 8 GHWA staff members
- 3 Western Australian health system representatives

As part of the workshop, guiding statements for GHWA's future service delivery were proposed and tested with participants, and these were used to inform the drafting of this service plan.

### Health Service Provider representative discussions

Discussions were held with representatives nominated by the executive leadership of EMHS, SMHS, CAHS, WACHS and PathWest in November 2023. Representatives held varying roles within their HSP, including consultant physician, Head of Department or Executive Director.

### Public consultation on the draft Plan

To note: This section will be updated after completion of the public consultation via the Department of Health's consultation platform Citizen Space.

# Appendix 2: Other genomic healthcare providers in WA

Whilst GHWA is the sole public provider of clinical genomics speciality services in WA, there are other services within the state that deliver genomic health care to the Western Australian public. As WA's only public provider of pathology services, PathWest provides genomic testing services across the state. These services include diagnostics, predictive testing, tumour profiling, carrier screening and prenatal testing for high-risk pregnancies, which PathWest provides to GHWA as well as other services within public hospitals, GPs, and certain other health professionals working in the private sector in WA. PathWest can also facilitate DNA samples being sent to an accredited laboratory interstate or overseas for a specific test to be conducted. Alternatively, some health professionals order tests direct from laboratories interstate or overseas. This is facilitated by their own networks or through research projects.

Additionally, other medical specialties have integrated genomics as part of routine health care without the involvement of GHWA. This includes the application of genomics to inform diagnosis and treatment, administer novel therapies, and monitor emerging public health threats. In these circumstances, the treating health professional has full oversight of the genomic healthcare pathway of the health consumer. For example, GPs are becoming increasingly involved in genomic testing. In many cases they refer health consumers suspected of having a genetic disease to the relevant medical specialist or GHWA. However, there are occasions where they will order tests directly. These are mostly non-invasive prenatal tests or single gene tests that are available through the Medicare Benefits Schedule.

# Appendix 3: GHWA's role in the implementation of the WA Genomics Strategy

The WA Genomics Strategy outlines a framework for future genomic health care in WA, guided by its five priority areas. A coordinated systemwide approach will be required to ensure this vision is realised, with collaborative efforts from all stakeholders and oversight from the Department of Health. As the sole public provider of clinical genomic specialty services in WA, GHWA will play a crucial role in supporting the future genomics ecosystem as outlined in the WA Genomics Strategy.

**Priority 1: Person- and Family-centredness**

Goal 1: To ensure consumers, carers, families and communities are at the heart of how genomic healthcare is designed, delivered and evaluated.

**Priority 2: Genomic Healthcare Services**

Goal 2: To achieve the optimal integration of genomic knowledge in the WA health system to deliver high value care that is timely, equitable and safe.

**Priority 3: Workforce, Education and Training**

Goal 3: To develop a sustainable health workforce with the appropriate capacity and necessary education and training to deliver genomic healthcare services.

**Priority 4: Digital Health and Data**

Goal 4: To establish the digital health and data solutions, protocols and standards needed to optimise the delivery of responsible genomic health care.

**Priority 5: Research and Innovation**

Goal 5: To have a health system that values and supports the creation and translation of genomics research and innovation.

**Box 2: The WA Genomics Strategy priorities and goals.**

All five priority areas of the WA Genomics Strategy (see Box 2) are relevant to GHWA's current operational model and future service planning. In recognition of the familial nature of genomic information, the WA Genomics Strategy emphasises that person- and family-centredness should be embedded at the core of all genomic services delivered within WA. This means that a person and family-centred approach will be taken in all aspects of genomic health care delivery, the management of genomic data, and genomic-related research. The focus will be on listening to consumers, enabling information exchange, facilitating choices and sharing decision-making, so that individual and family needs, goals and preferences are met as part of a collaborative approach, while also supporting safer and more effective care. In doing so, genomic providers will respect the ethnic, cultural and socio-economic diversity of consumers and families.

The document also highlights the crucial role of genomic healthcare services such as GHWA in supporting the equitable and person- and family-centred integration of new genomic advancements into the Western Australian health system in a timely manner. This will require a coordinated approach between PathWest, GHWA and other providers of health services to grow genomic capacity across the Western Australian health system. New and innovative service models will be needed to ensure that genomic advancements can be incorporated into the Western Australian health system in a safe and equitable manner to bring the greatest benefit to Western Australians close to where they live.

It is advised in the WA Genomics Strategy that the efficient and sustainable implementation of genomic advances will require a coordinated effort and investment to develop, attract and retain the required specialised genomic workforce (which includes GHWA's staff), as well as increase the genomic literacy across the broader healthcare workforce. It also notes the need for digital solutions that enable the appropriate access and use of genomics in health care, which encompasses the efficient, appropriate and secure collection, storage and sharing of genomic and phenotypic data across the Western Australian health system. Finally, the WA Genomics Strategy recognises the importance of encouraging health professionals (including those employed by GHWA) to collaborate in research and innovation projects to support the translation of genomic knowledge into healthcare services.