



Development of a Clinical Service Plan for the Genetic Services of Western Australia: Project Summary

The aim of this project is to review the current service model of the [Genetic Services of Western Australia](#) (GSWA) and co-design a clinical service plan to enable the provision of an equitable state-wide service that appropriately supports the future genomic health care needs of WA. The clinical service plan is being developed using a co-design approach to embed the experiences, needs and ideas of stakeholders in the future direction of GSWA services. The clinical service plan is estimated to be completed in August 2024.

About the Genetic Services of Western Australia

GSWA is the only public provider of clinical genetics and genetic counselling in WA. They operate as a state-wide service and provide a comprehensive diagnostic and confidential genetic counselling service for people with, or are at increased risk of, developing a genetic or inherited condition.

Services are mainly provided in an outpatient setting, either at their premises at King Edward Memorial Hospital or through a network of metropolitan and regional outreach clinics. Patients can be referred via their general practitioner, specialist, hospital inpatient wards or outpatient clinics (both public and private).

There are three sub-specialty services run by GSWA:

- **Obstetrics and General Genetic Services:** provides services to:
 - adults who have or are suspected of having a genetic disorder
 - adults who have a family history of a specific genetic disorder and are considering pregnancy
 - pregnant patients whose unborn child has a higher risk of a genetic disorder
- **Familial Cancer Program:** provides services to patients who have or are at risk of an inherited cancer syndrome.
- **General Paediatric Services:** provides services to children who have or are suspected of having a genetic disorder.

Outside of these broad sub-specialities, GSWA also provide disease-specific services integrated into multidisciplinary clinics with other medical specialities (e.g. cardiogenetics, renal genetics). GSWA staff also provide inpatient ward consultations to King Edward Memorial Hospital and Perth Children's Hospital when clinically required.

Laboratory services are provided to GSWA by PathWest, the state pathology service. This includes both screening and diagnostic testing on specimens including blood, skin, and foetal cells. Testing may be employed for antenatal or postnatal genetic diagnosis, assessing carrier status, or prediction of adult-onset conditions.

Please see the [GSWA website](#) to find out more about the services they provide.

Project rationale

Rapid changes in genomic technology over recent years have led to an increase in demand for the clinical genetic services provided by GSWA from both health professionals and consumers across WA. Purposeful and adaptive service planning is required to ensure GSWA can manage this demand in a timely manner and provide equitable, person and family-centred genomic health care. To meet the needs of people living in rural and remote areas, new and innovative models of service delivery will need to be explored. In addition, there will need to be consideration of how the diverse needs of consumers across various ethnic, social and cultural groups can be met. The development of a clinical service plan for GSWA will help the service to address these current and future needs in a way which brings the greatest benefit to all Western Australians.

Objectives

The objectives of this project are to:

- Review the current operating model and services provided by GSWA and the associated strengths, opportunities, risks, and issues.
- Conduct a current state assessment of clinical service plans for genomics in Australia and internationally.
- Engage with key stakeholders and consumers of GSWA to co-design a proposed clinical service model for genomic health care delivered by GSWA.
- Co-design a clinical service plan for GSWA to provide genomic health care across WA over a 10-year period.

Scope

The project scope includes the services provided by GSWA from the time a patient receives a referral to GSWA to when the patient case is closed.

The project scope excludes the:

- Patient pathway through the WA health system prior to referral to GSWA and following referral back to primary or specialist care
- Clinical management models applied by geneticists and genetic counsellors
- Governance and reporting pathways for GSWA
- Implementation or future infrastructure needs
- Provision of genomic health care by private health care providers

Items out of scope for the development of the clinical service plan are expected to be addresses subsequently and may form part of the ongoing implementation of the Strategy.

Project context

The [WA Genomics Strategy 2022-2032: Towards precision medicine and precision public health](#) (the Strategy) was released by the Department of Health in October 2022. The Strategy aims to coordinate and maximise stakeholder efforts to enable efficient, effective, ethical and equitable translation of genomics knowledge into the WA health system. The development of a clinical service plan for GSWA is a key deliverable within Priority 2 ('Genomics Healthcare Services') of the Strategy.

This project also aligns with the strategic priorities of the: [Western Australian Department of Health Corporate Plan 2022 – 2023](#); the [North Metropolitan Health Service, Our Strategic Plan: 2020 – 2025: One team, many dreams. One integrated NMHS](#); and the [Sustainable Health Review: Final Report to the Western Australian Government](#).

Stakeholder oversight

The Office of Population Health Genomics, Department of Health is the project manager and works in close collaboration with the GSWA.

To facilitate as close to a co-design approach as possible, two stakeholder oversight groups have been formed to guide this project. A GSWA Clinical Service Plan Working Group (the Working Group) has been established under the WA Genomics Strategy Implementation Committee (which assists with implementation of the Strategy) to provide strategic guidance and expert advice to the project manager on clinical service planning and genomic health care.

The GSWA Clinical Service Plan Co-Design Team (Co-Design Team) has been established to guide the co-design approach and provide guidance on wider stakeholder engagement. The Co-Design Team consists of an equal balance of people with lived and learned experience of genetic conditions, including consumers, representatives from key community organisations, staff at GSWA and Department of Health WA project team members.

Co-design approach

The central priority of the [WA Genomics Strategy 2022-2032](#) is 'Person and Family-Centredness', which stipulates that people should be at the centre of how genomics healthcare is developed, designed and evaluated. The clinical service plan is therefore being co-designed with consumers and other stakeholders on the basis that partnering with them from the beginning of the project will help to ensure that the resulting product best reflects their experiences, ideas and needs.

As part of this approach the Co-Design Team are part of the project's Working Group and both stakeholder oversight groups are co-chaired by a lived experience consultant and a representative of the Project Manager.

Public consultation

A key part of this project is a series of engagement activities to gather information from key stakeholders to inform the clinical service plan. These engagement activities have been co--designed by the Co-Design Team with input from the Working Group and a diverse range of stakeholders. Individuals and groups identified as GSWA stakeholders who will be recruited to participate in engagement activities include:

- People referred to GSWA within the last 10 years, and/or their parents or carers
- GSWA staff
- Primary care and specialist clinicians who are past, current and potential future referrers to GSWA
- Support service staff who support GSWA patients during appointments (e.g. interpreters)
- Clinical planners and health service provider executives
- Health consumer organisations

The activities planned are:

- **Surveys** – Two online surveys will remain open for the duration of the stakeholder engagement period (one for community members with lived experience of GSWA and one for clinicians and support service staff). These will capture the respondents' experience of, and insights into, GSWA and gather expressions of interest (EOI) to participate in later activities.
- **Interviews** – Selected interviews will aim to clarify the current experiences of GSWA patients or carers of patients, clinical referrers and health service providers and used to identify important issues to explore further in later activities.

- **Focus groups** – Multiple focus groups will be conducted to explore key issues with specific stakeholder groups. These stakeholder groups will include GSWA patients/carers, GSWA staff and primary care referrers who have volunteered to participate via the EOI.
- **Combined stakeholder workshop** – A workshop combining stakeholders with lived and learned experience will be conducted to consolidate the findings from the previous stakeholder engagement activities and co-design future priorities and recommendations for the clinical service plan.
- **Post draft survey** – A survey will also be conducted to obtain feedback on the draft clinical service plan prior to final approval. Any stakeholder who has submitted an EOI will be invited to participate in this consultation process.

Further information

For more information on this project, please contact the Office of Population Health Genomics at genomics@health.wa.gov.au.

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