



NSW HEALTH GENOMICS STRATEGY

Implementation Plan 2021-25

Developed in co-design with
consumers, clinicians, researchers
and health managers



FOREWARD

The NSW Health Genomics Strategy Implementation Plan 2021-25 demonstrates NSW Health's ongoing commitment to be at the forefront in incorporating genomics into the NSW Health system.

Over the next five years, NSW will build upon strong foundations in clinical genomics and work to deliver priorities to enhance disease management and prevention.

I wish to thank the Local Health Districts, Specialty Health Networks, NSW Health Pathology, the Agency for Clinical Innovation, the Health Education and Training Institute, and eHealth NSW which have all led the implementation and delivery of initiatives since the release of the first phase implementation plan two years ago.

This plan for implementation represents the collaborative efforts and ongoing commitment of time and expertise of the members of all the supporting governance committees.

I wish to thank all committee members, and representatives from their various networks in co-designing the priorities for action in NSW.

Elizabeth Koff
Secretary, NSW Health

Overview

The NSW Health Genomics Strategy was released in August 2017. The Strategy articulates a shared vision for clinical genomics in NSW, promoting collaboration to maximise opportunities for partnership and optimal use of resources.

The vision is that by 2025, NSW Health will be recognised as a leader in the development and use of appropriate genomic technologies in healthcare and public health for the benefit of the NSW population. It will be a preferred partner for industry in (gen)omics research, education and training, with effective translation into clinical practice and public health initiatives. This will attract talent and investment to NSW to help realise the promise of genomics.

Realising the vision

The NSW Health Genomics Strategy implementation is considered in three phases: Strengthen the foundations (2 years), Enhance disease management and prevention (2-7 years) and Towards precision medicine (7 years and beyond). The rapid pace of change in clinical genomics is unprecedented, and therefore whilst three distinct phases have been described it is anticipated that projects and initiatives will flow between phases as they develop and genomic technologies evolve.

The NSW Health Genomics Strategy Implementation Plan 2021-25 supports the second phase of the Strategy, 'Enhance disease management and prevention'.



Developing the Phase 2 Implementation Plan

The second phase of the Genomics Strategy (2021-25) will focus on enhancing disease management and prevention. Launched in September 2020, a co-design, or participatory planning approach, was adopted to develop the implementation plan.

NSW stakeholders, numbering over 200, including consumer representatives, clinicians, scientists, service managers, health planners, researchers, academics and policy makers participated in a series of facilitated virtual workshops. Participants worked together to formulate the change levers required to advance clinical genomics and realise the vision of NSW Health Genomics.

This Plan, the culmination of the co-design effort, consolidates the priority concepts and key actions for implementation of the Genomics Strategy over the next five years.

Governance

The Genomics Steering Committee was established during Phase 1 to oversee the implementation of the strategy. Three committees aligned to the Phase 2 focus areas will support implementation for the next five years (see Figure 1).

Partnerships

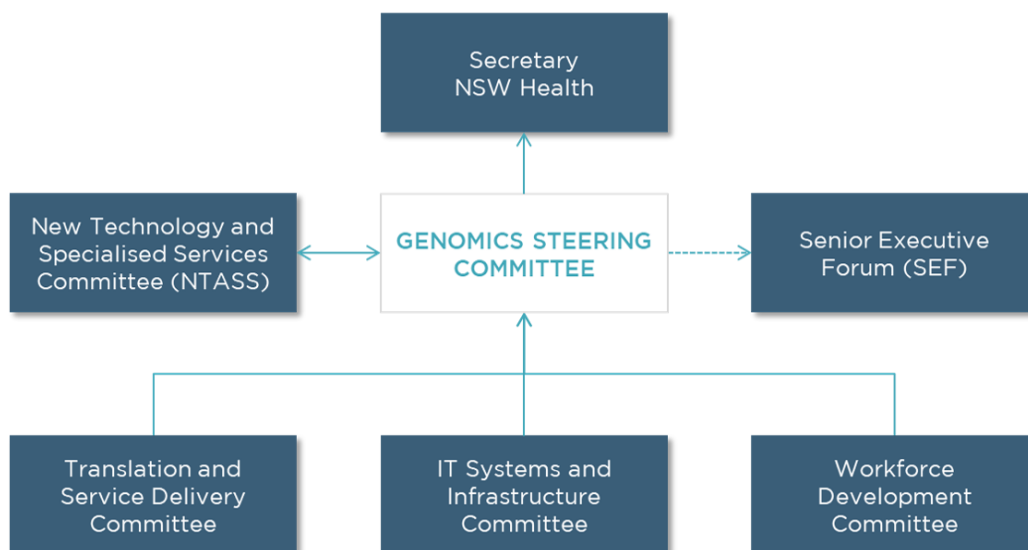
The NSW Health Genomics Strategy promotes collaboration and coordination to support the integration of clinical genomics into everyday health care. This involves identifying and bringing together key partners within and beyond NSW Health.

Engaging with the NSW community as equal partners across the three focus areas will be essential in the development of genomic services across the state. Consumers and patients will be informed and supported to make appropriate health and wellness choices for the benefit of themselves, their families and the community.

NSW Health is working together with the Commonwealth, state and territory governments to foster consistency so that the potential benefits of genomics are harnessed for the benefit of all Australians.

To realise the health benefits of genomic technologies into the future a new level of connectedness and collaboration across stakeholders nationally and internationally will be required. Many of our stakeholders are involved in inter-jurisdictional, national and international initiatives which deliver essential opportunities to engage beyond NSW.

Figure 1: NSW Health Genomics Strategy Governance Structure



Achievements to date

Phase 1 of the strategy was to 'strengthen the foundations' of clinical Genomics in NSW. Significant progress has been made across all of the strategy's six recommendations with examples provided below.

1. Establish a Governance Committee to guide the strategic direction for clinical genomics in NSW.

- The NSW Health Genomics steering committee was established in January 2018.

2. Enhance, simplify and expedite the mechanisms for assessing the clinical need, validity and utility of new developments in health genomics and prioritise their potential for translation into the NSW public health system

- Published review of existing frameworks for translating genomics research to clinical practice
- Mapped mechanisms and concepts to inform the NSW Health Genomics Translational Framework
- Terms of reference established for an Expert Advisory Group to advise the NSW Health system on translation of new genomic technologies

3. Develop new service delivery models linked to clinical pathways that incorporate genomic and digital advances to provide safe and equitable access across NSW.

- NSW Health Pathology launched the first public Clinical Genome and Exome Sequencing Service in March 2020. This included the procurement of Massively Parallel Sequencing infrastructure to grow the capability in NSW to deliver exome and whole genome sequencing
- Commencement of pilot service delivery model projects in Neurofibromatosis, Genetic Testing in Intellectual Disability, Immune Effector Cell therapies, and gene therapies for Genetic Eye Disease, and Paediatric Neurology.
- Pilot newborn bloodspot screening for Spinal Muscular Atrophy (SMA) and Severe Combined Immunodeficiency (SCID), and add screening for Congenital Adrenal Hyperplasia (CAH), to the NSW Bloodspot Screening Program. The addition of SMA and SCID has been extended to 30 June 2022.

4. Work with relevant parties to define the information standards, protocols and enabling infrastructure required to integrate clinical genomics into mainstream care.

- Development of standardised parameters for genomic test result reporting
- Published report on the genomic data sharing landscape in NSW
- Development of a cloud-based infrastructure model to support the storage and interpretation of genomic data.
- Market scan of genomics ICT products to inform future decision making

5. Work with relevant NSW stakeholders and national bodies to identify future workforce requirements, including awareness and genomic literacy within NSW Health, and develop a plan to address these needs.

- Cancer Institute NSW awarded four grants for clinical and research training in cancer genetics
- Publication of career videos with leading NSW clinicians published on the NSW Health Map My Health Career website
- Workforce functions developed through workshops and patient journey mapping for genomics use case
- Development of education resources for Paediatricians on exome sequencing for childhood syndromes

6. Work with key stakeholders, including general practitioners and Primary Health Networks, to engage the community regarding clinical genomics to build and sustain public confidence.

- Development of NSW Health Clinical genetic/genomic consent forms
- Gap and needs analyses of genomics resources for consumers and health professionals to identify priorities for future developments.
- 'Understanding Genomics' eLearning resource developed and published on MyHealthLearning.
- Development of 'HealthPathways' for General Practitioners to access accurate information and referral pathways for Genomics.

DELIVERING THE VISION – STRATEGIES FOR ACTION

The following pages outline the priority concepts collaboratively developed by NSW stakeholders. The Phase 2 Implementation Plan has three focus areas to enhance disease management and prevention.

Each priority concept is matched to key actions and the identified bodies for responsibility. The indicative project time frames are “short” if the implementation is in the next 12-18 months, “medium” in the next 18-36 months and ‘long’ if they stretch into years four and five

FOCUS AREA 1

Advances in health genomics are incorporated into new and existing clinical pathways to provide safe, cost-effective, equitable and beneficial disease prevention and management across NSW.

Priority Concepts	Key Actions	Partners	¹ Time Frame
Support equitable access to clinical genomics, with a focus on regional, rural and remote areas	Embed, scale and sustain multidisciplinary clinical genomics ² model(s) of care.	Consumers, Local Health Districts and Specialty Health Networks (LHD/SHNs), NSW Agency for Clinical Innovation (ACI), NSW Health Pathology (NSWHP), NSW Ministry of Health (MoH)	Medium
	Develop tool(s) to support the coding and capture of activity as genomic services evolve in response to emerging model(s) of care	ACI, LHD/SHNs, MoH, NSWHP	Short
	Develop and test tool(s) to support triage and referral pathways. This will include development of HealthPathways ²	Consumers, ACI, LHD/SHNs, MoH,	Medium
Expedite translation of safe and effective genomics innovations into the NSW public health system	Develop a ² framework and supporting tool(s) for the appropriate and consistent translation of genomic research into clinical practice	Consumers, LHD/SHNs, MoH,	Short
	³ Evaluate the translational framework through demonstrator project(s)	LHD/SHNs, MoH	Short
	Provide advice to NSW Health on translational omics	³ Translational medicine expert advisory group	On-going

- 1 **Short:** To be implemented in the next 12-18 months
Medium: To be implemented in the next 18-36 months
Long: To be implemented in year 4 to 5
2 Project commenced in 2018-20
3 Key action (Long-term) carried over from 2018-20

FOCUS AREA 2

Enabling systems and infrastructure to support access and integration of workflows for clinical genomics that meet consumer needs and expectations.

Priority Concepts	Key Actions	Partners	¹ Time Frame
Embed an integrated genomics infrastructure model for NSW ²	Continue to monitor ² requirements for data management and governance, including ³ access levels	Consumers, eHealth NSW, Local Health Districts and Specialty Networks (LHD/SHNs), NSW Agency for Clinical Innovation (ACI), NSW Health Pathology (NSWHP), NSW Ministry of Health (MoH)	On-going
	Develop standards to guide the uptake of genomics IMT products that considers user and consumer needs and experience	Consumers, eHealth NSW, MoH, NSWHP	Medium
	Implement ² infrastructure to integrate genomic data across existing systems	ACI, eHealth, MoH, NSWHP	Long
Develop systems and tools to enable ordering, tracking and reporting of genomic test results	Implement a single electronic genomic ² test ordering platform	eHealth, LHD/SHNs, NSWHP	Medium
	Develop an electronic tracking system for genomic tests	Consumers, eHealth, LHD/SHNs, NSWHP	Medium
	Implement and integrate ² standard test result reporting with existing and emerging systems to ³ support sharing of clinical information across NSW and Australia	Consumers, eHealth, LHD/SHNs, NSWHP	Long
Streamline digital consent to clinical genomic testing	Establish digital consent requirements for clinical genomic testing	ACI, Consumers, eHealth, LHD/SHNs, MoH, NSWHP	Short
	Build and test digital consent for clinical genomics use case(s)	ACI, Consumers, eHealth, LHD/SHNs, MoH, NSWHP	Short
	Integrate patient and health professional education resources with digital consent	ACI, Consumers, eHealth, LHD/SHNs, MoH, NSW Centre for Genetics Education (CGE)	Medium

- 1 **Short:** To be implemented in the next 12-18 months
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Long: To be implemented in year 4 to 5
2 Project commenced in 2018-20
3 Key action (Long-term) carried over from 2018-20

FOCUS AREA 3

A health workforce with improved knowledge, skills and capabilities to develop, use and apply clinical genomics to optimise patient care.

Priority Concepts	Key Actions	Partners	¹ Time Frame
Enhance point of care access to genomics education for the health workforce	Develop education website design concept(s) ² to meet health professional and consumer requirements	Consumers, eHealth NSW, Local Health Districts and Specialty Networks (LHD/SHNs), NSW Agency for Clinical Innovation (ACI), NSW Centre for Genetics Education (CGE), NSW Ministry of Health (MoH)	Short
	Redesign the educational resources portal for health workers and consumers	ACI, CGE, Consumers, eHealth, LHD/SHNs, MoH	Medium
Continue to upskill the health workforce to use clinical genomics applications	Develop training needs assessment tool(s) for workforces with emerging responsibilities in the delivery of clinical genomics	ACI, CGE, Consumers, Health Education and Training Institute (HETI), LHD/SHNs, MoH	Medium
	Incorporate genomics education into continuing professional development	CGE, HETI, LHD/SHNs, MoH	Long
	Continue to develop systems to embed genomics within undergraduate education	CGE, HETI, LHD/SHNs, MoH	Medium
Implement strategies to meet required workforce functions ² for genomics clinical pathways	Strengthen capability in genomic workforce planning enabled by contemporary workforce data and tools	ACI, HETI, LHD/SHNs, MoH, NSW Health Pathology (NSWHP)	Long
	Workforce champions and educators are utilised to support the delivery of clinical genomics use cases	ACI, Consumers, LHD/SHNs, MoH	Medium

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2 Project commenced in 2018-20



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