



# NSW HEALTH GENOMICS STRATEGY Implementation Plan 2018-20

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



# FOREWORD

It is with great pleasure that I present to you the *NSW Health Genomics Strategy Implementation Plan 2018-20*.

The release of this plan demonstrates NSW Health's commitment to embedding the promise of genomics into the NSW Health system. Over the next two years and beyond, NSW will work to deliver key foundational initiatives in clinical genomics to improve access to patient care that is value-based, integrated and connected with all parts of the health system.

This plan for implementation is a direct result of the significant effort by members of all the supporting governance committees who have also engaged their various networks to co-design these priorities for action in NSW. I wish to thank all committee members for their ongoing commitment of time and expertise to realise our collective vision for genomics in NSW.

**Elizabeth Koff**

Secretary, NSW Health

## Overview

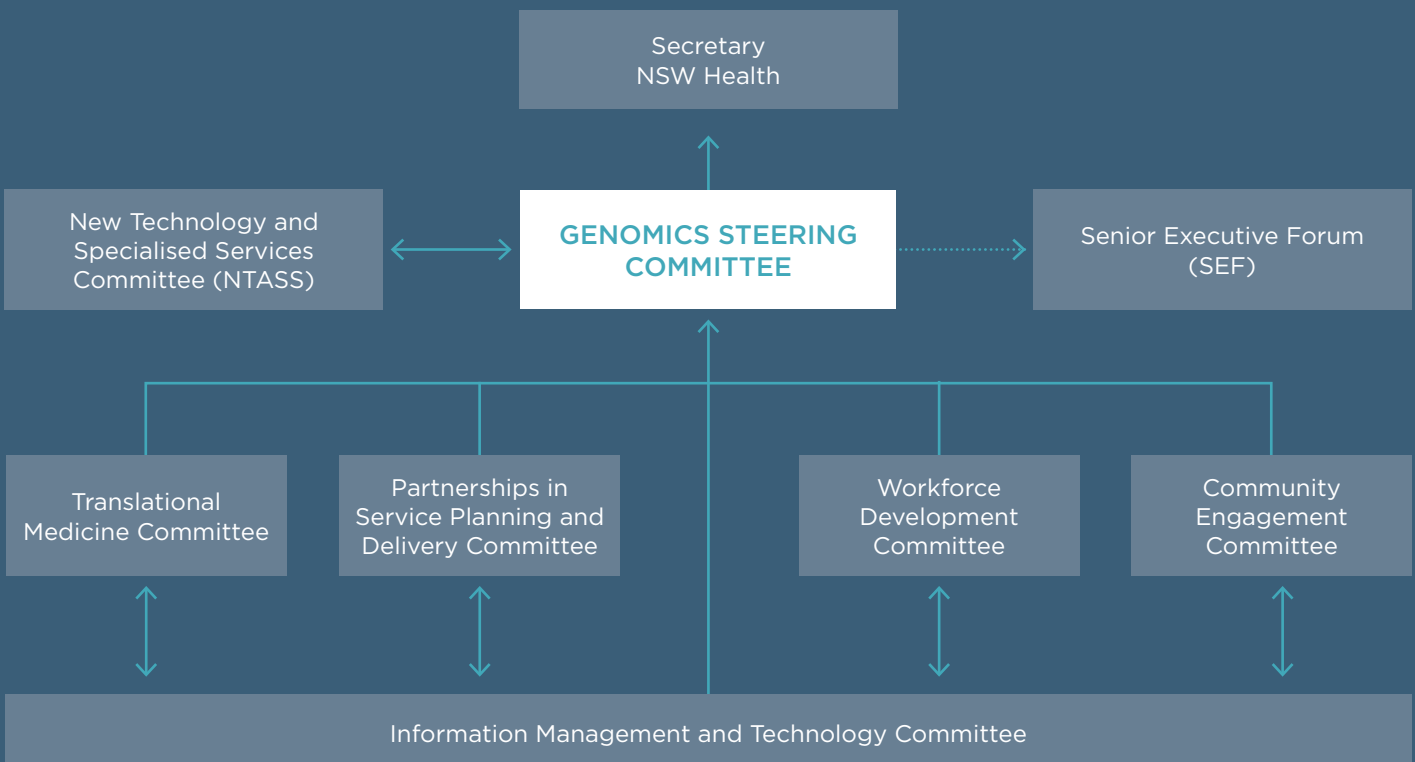
The *NSW Health Genomics Strategy* was released in August 2017 following extensive stakeholder consultation. The Strategy articulates a shared vision for clinical genomics in NSW, promoting collaboration to maximise opportunities for partnership and optimal use of resources.

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.

## Governance

The Genomics Steering Committee has been established to oversee the development of the implementation plan for Phase 1 of the Strategy: *Strengthen the Foundations*, and the establishment and work of five committees (see Figure 1) to ensure the delivery of the recommendations.

Figure 1 NSW Health Genomics Strategy Governance Structure



## Partnerships

One of the guiding principles of the Strategy is to promote 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.

NSW was actively involved in the development of the National Health Genomics Policy Framework and Implementation Plan, which provided a valuable opportunity to align the Strategy with the national agenda. As the implementation of the national Framework and the NSW Strategy progress, alignment and collaboration between the jurisdictions, the Commonwealth, research organisations, universities, industry and the philanthropic community will be essential for success.

For NSW and Australia to realise the full potential of precision medicine into the future the ability to forge international relationships is also essential. Many of our stakeholders are involved in inter-jurisdictional, national and international initiatives, such as the work of the Australian Genomics Health Alliance (Australian Genomics) and the Medical Research Futures Fund, which provide opportunities to engage beyond NSW.

## Developing the implementation plan

The rapid pace of change in clinical genomics is unprecedented, and therefore it has been difficult to identify precise timeframes. Therefore implementation planning has been 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).

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.

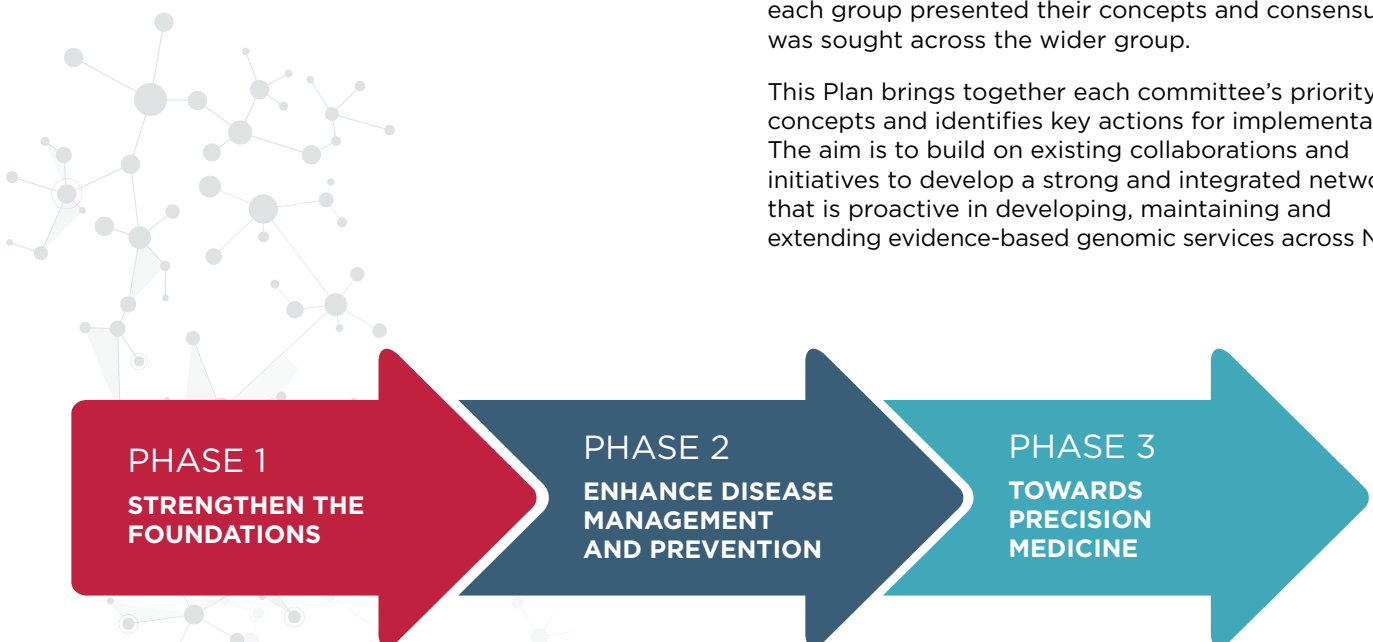
The plan builds on the Strategy's six recommendations:

1. Establish a Governance Committee to guide the strategic direction for clinical genomics in NSW.
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.
3. Develop new service delivery models linked to clinical pathways that incorporate genomic and digital advances to provide safe and equitable access across NSW.
4. Work with relevant parties to define the information standards, protocols and enabling infrastructure required to integrate clinical genomics into mainstream care.
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.
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. This includes working with consumers as equal partners to develop services that reflect their needs and preferences in line with ethical, legal and professional standards.

A co-design, or participatory planning approach, was adopted to develop the Plan. The five subject specific committees were established in early 2018 with membership from a broad range of NSW stakeholders including clinicians, scientists, researchers, academics, service managers, health planners, community representatives and policy makers.

Each of the committees participated in facilitated workshops to identify priority concepts that will act as change levers to create momentum and opportunities to bring wide groups of stakeholders together. This work culminated in a multi-committee workshop where each group presented their concepts and consensus was sought across the wider group.

This Plan brings together each committee's priority concepts and identifies key actions for implementation. The aim is to build on existing collaborations and initiatives to develop a strong and integrated network that is proactive in developing, maintaining and extending evidence-based genomic services across NSW.



# DELIVERING THE VISION - STRATEGIES FOR ACTION

The following pages outline the priority concepts developed by each of the participatory committees. Each key concept is matched to key actions and the identified body for responsibility. While most project timeframes focus on Phase 1 (the first 2 years), it is acknowledged that some projects may extend into Phase 2 and provision has been made for timeframes of up to 36 months.



## RECOMMENDATION 1

Establish a governance committee to guide the strategic direction for clinical genomics in NSW.

NSW Priority Concepts	Key Actions	Responsible	Status
Establish NSW genomics steering committee	<ul style="list-style-type: none"> <li>Develop terms of reference to outline the role and responsibilities of the steering committee</li> <li>First meeting held on 30 January 2018</li> </ul>	Ministry of Health	Complete
Establish five sub-committees with responsibility for addressing priority actions	<ul style="list-style-type: none"> <li>Develop terms of reference for each of the subject specific committees:                             <ul style="list-style-type: none"> <li>Translational Medicine</li> <li>Partnerships in Service Planning and Delivery</li> <li>Workforce Development</li> <li>Community Engagement</li> <li>Information Management and Technology</li> </ul> </li> <li>Each committee to develop a work plan</li> </ul>	Ministry of Health	Complete
Steering committee provides continuing strategic guidance on the implementation of the genomics strategy	<ul style="list-style-type: none"> <li>Subject specific committees to report bi-annually on progress against work plans</li> <li>Steering committee to report bi-annually to the Secretary, NSW Health</li> </ul>	Committee Chairs	On-going
		Steering Committee	On-going



<sup>1</sup> **Short:** To be implemented in the next 12 - 18 months,  
**Medium:** To be implemented in the next 18 - 24 months  
**Long:** To be implemented in the next 24 - 36 months



## RECOMMENDATION 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.

NSW Priority Concepts	Key Actions	Responsible	Time frame <sup>1</sup> Short/Medium/ Long
Develop a framework to translate (gen)omic research projects into mainstream clinical service delivery	<ul style="list-style-type: none"> <li>Develop draft framework and 'readiness criteria'</li> </ul>	Translational Medicine Committee/ participating districts and networks	Short
	<ul style="list-style-type: none"> <li>Framework to include a NSW Health genomics 'utility card' to guide research/clinician applicants for funding</li> </ul>		Long
	<ul style="list-style-type: none"> <li>Test framework with demonstrator projects</li> </ul>	Ministry of Health	Short
	<ul style="list-style-type: none"> <li>Introduction of the Office for Health and Medical Research (OHMR) omics translational research program</li> </ul>		Short
Establish an expert body to provide advice on: <ul style="list-style-type: none"> <li>potential translational omics research projects</li> <li>local decision making</li> <li>NSW Health service provision</li> </ul>	<ul style="list-style-type: none"> <li>Develop terms of reference for the NSW Health genomics advisory body including membership</li> </ul>	Translational Medicine Committee/ Ministry of Health	Short
	<ul style="list-style-type: none"> <li>Provide advice to the NSW Health new technology assessment process as required</li> </ul>	Translational Medicine Committee	Short
Develop a framework for NSW Health engagement with the commercial sector in genomics	<ul style="list-style-type: none"> <li>Develop draft framework</li> </ul>	Translational Medicine Committee/ Ministry of Health	Medium
	<ul style="list-style-type: none"> <li>Create a consultation and communications plan for the engagement framework</li> </ul>		Medium
	<ul style="list-style-type: none"> <li>Test framework with demonstrator projects</li> </ul>	/participating districts and networks	Long



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### RECOMMENDATION 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 Priority Concepts	Key Actions	Responsible	Time frame <sup>1</sup> Short/Medium/ Long
Streamline access to clinical genetics services	<ul style="list-style-type: none"> <li>Cancer Genetics Waitlist Management pilot project</li> </ul>	Cancer Institute NSW/ participating districts and networks	Medium
	<ul style="list-style-type: none"> <li>Develop tools to support triage and referral pathways</li> </ul>	Northern Sydney Local Health District/Ministry of Health	Long
	<ul style="list-style-type: none"> <li>Test tools in a mitochondrial disease pilot project</li> </ul>		Long
Improve access to genomics testing services	<ul style="list-style-type: none"> <li>Design and develop a brokerage model for ordering genetic and genomic tests, including a digital solution to data warehousing</li> </ul>	NSW Health Pathology/ participating districts and networks	Medium
	<ul style="list-style-type: none"> <li>Test model with demonstrator sites</li> </ul>		Long
Develop new service delivery models	<ul style="list-style-type: none"> <li>Undertake a baseline audit to describe clinical genomics services in NSW</li> </ul>	Ministry of Health	Complete
	<ul style="list-style-type: none"> <li>Develop guidance on the establishment of genetic and genomic outpatient services</li> </ul>	Ministry of Health	Medium
	<ul style="list-style-type: none"> <li>Develop genetics/clinical genomics model(s) of care</li> </ul>	Agency for Clinical Innovation	Medium
	<ul style="list-style-type: none"> <li>Test model(s) with demonstrator sites</li> </ul>		Long



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## RECOMMENDATION 4

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

NSW Priority Concepts	Key Actions	Responsible	Time frame <sup>1</sup> Short/Medium/ Long
Develop a standard format for reporting genomic test results in the Electronic Medical Record (eMR) and NSW Notifiable Conditions Information Management System (NCIMS)	<ul style="list-style-type: none"> <li>Develop and pilot a standard report for three use cases in the areas of cancer, rare diseases and pathogen genomics</li> </ul>	NSW Health Pathology/ Information Management and Technology Committee	Medium
	<ul style="list-style-type: none"> <li>Align reports with interstate and national approaches to support sharing of genomic test results for clinical use across jurisdictions</li> </ul>		Long
Determine the need for new data governance framework/s in NSW to support data sharing	<ul style="list-style-type: none"> <li>Legal review of existing privacy provisions for genomic data storage and sharing (including between state departments and jurisdictions)</li> </ul>	Ministry of Health	Short
	<ul style="list-style-type: none"> <li>Update data governance frameworks as required, incorporating legal review findings</li> </ul>	Ministry of Health /eHealth NSW	Medium
	<ul style="list-style-type: none"> <li>Identify appropriate access level for each clinical role to view and/or manage genomic information in the eMR</li> </ul>	Ministry of Health/Agency for Clinical Innovation	Long
Develop a next generation infrastructure model to support integration of genomic data with the eMR and NSW Health Pathology	<ul style="list-style-type: none"> <li>Develop a centralised infrastructure model and information sharing architecture to integrate genomic data across platforms, including the eMR and NSW Health Pathology</li> </ul>	NSW Health Pathology/ eHealth NSW/ participating districts and networks	Short
	<ul style="list-style-type: none"> <li>Pilot identified platforms and interoperability at selected sites, as a proof of concept for the transfer of and access to genomic data within NSW Health</li> </ul>		Medium





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## RECOMMENDATION 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.

NSW Priority Concepts	Key Actions	Responsible	Time frame <sup>1</sup> Short/Medium/ Long
Marketing a career in genomics	<ul style="list-style-type: none"> <li>Develop genomics related content for the NSW Health <i>Map My Health Career</i> website</li> </ul>	Workforce Development Committee	Short
	<ul style="list-style-type: none"> <li>Map the promotional materials that are currently available for genomics and identify any gaps</li> </ul>	Workforce Development Committee	Short
	<ul style="list-style-type: none"> <li>Develop and pilot genomics workforce promotional materials for students, general practice, clinicians and the general public</li> </ul>	Workforce Development Committee	Short
Identify and describe genomics workforce roles that are critical to current and anticipated future workforce demands	<ul style="list-style-type: none"> <li>Map patient genomic journeys and interactions with various workforce roles</li> </ul>	Workforce Development Committee	Short
	<ul style="list-style-type: none"> <li>Develop and test scenarios to see what genomics workforce is moving towards</li> </ul>		Medium
	<ul style="list-style-type: none"> <li>Develop/collate model role descriptions</li> </ul>		Medium
	<ul style="list-style-type: none"> <li>Capture current workforce data and map existing genomics workforce in NSW Health</li> </ul>	Ministry of Health	Short
	<ul style="list-style-type: none"> <li>Deliver a grants program to support advanced training in cancer genetics</li> </ul>	Cancer Institute NSW	Short
Improve genomics education by forming a genomics expert team to support curriculum development, in collaboration with NSW education and curriculum stakeholders	<ul style="list-style-type: none"> <li>Develop overview of current education/curriculum genomics activities in NSW</li> </ul>	Workforce Development Committee	Short
	<ul style="list-style-type: none"> <li>Undertake a needs analysis of education/curriculum across key stakeholders</li> </ul>		Medium
	<ul style="list-style-type: none"> <li>Identify where existing resources can be better used or new resources/plans are required</li> </ul>		Medium



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## RECOMMENDATION 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. This includes working with consumers as equal partners to develop services that reflect their needs and preferences in line with ethical, legal and professional standards.

NSW Priority Concepts	Key Actions	Responsible	Time frame <sup>1</sup> Short/Medium/ Long
Building genomic literacy in 'first responder' clinicians	<ul style="list-style-type: none"> <li>Develop and implement a single consent form for genetic-genomic testing</li> </ul>	Agency for Clinical Innovation	Short
	<ul style="list-style-type: none"> <li>Condense current genetic testing policy documents into one</li> </ul>	Agency for Clinical Innovation	Long
	<ul style="list-style-type: none"> <li>Review information available to 'first responder' clinicians and identify gaps/barriers to genomic literacy</li> </ul>	Agency for Clinical Innovation	Medium
	<ul style="list-style-type: none"> <li>Develop a demonstrator project to build genomic literacy in 'first responder' clinicians</li> </ul>		Long
Empowering consumers to ask the right questions about their care	<ul style="list-style-type: none"> <li>Develop a patient resource to accompany the single consent form for genetic-genomic testing</li> </ul>	Agency for Clinical Innovation	Medium
	<ul style="list-style-type: none"> <li>Review information available to patients and consumers to identify gaps and/or barriers to their understanding of genetic-genomic issues</li> </ul>	Agency for Clinical Innovation	Medium
	<ul style="list-style-type: none"> <li>Develop a demonstrator project to test consumers' ability to ask the right questions about their care</li> </ul>	Agency for Clinical Innovation	Long
Providing trusted sources of information for clinicians and consumers	<ul style="list-style-type: none"> <li>Review current information available to clinicians, patients and consumers on the Centre for Genetics Education website to identify frequently accessed resources</li> </ul>	Centre for Genetics Education	Short
	<ul style="list-style-type: none"> <li>Undertake a clinician needs assessment to identify their information requirements and preferred mode of delivery</li> </ul>		Short

## Next steps

The priorities identified in this Plan will form the basis of the detailed work plans for each of the subject specific committees.

Progress against the work plans will be reported on a quarterly basis to the steering committee.

## Monitoring and reporting

It should be noted that this Plan does not attempt to address all issues relating to genomics; rather it aims to build the foundations for mainstreaming clinical genomics into public healthcare.

An annual report on progress will be prepared to monitor implementation of the NSW Health Genomics Strategy.

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