



NSW Genetic Counsellor Workforce

HORIZONS SCANNING AND SCENARIO GENERATION PROJECT
 HEALTHCONNECT CONSULTING



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Terminology: Within NSW Health, the term ‘Aboriginal’ is generally used in preference to ‘Aboriginal and Torres Strait Islander’, in recognition that Aboriginal people are the original inhabitants of NSW (refer NSW Health Policy Directive https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2005_319 PD2005_319).


Disclaimer: The purpose of this document is to outline the methodology, approach and themes raised by the literature and genetic counsellor stakeholders to inform the Workforce Modelling phase of the NSW Ministry of Health’s Workforce Planning Methodology. It should be noted that the views expressed in the report are not necessarily those of the NSW Ministry of Health.

Executive summary

NSW Genetic Counsellor Workforce Vision 2030


A strong and valued workforce operating at full scope of practice, in collaboration with health professionals across all specialties, enabled to provide timely and equitable services to the population.

NSW Health workforce profile



- 58.1 FTE working across 14 LHDs/1 SHN/ NSW Health Pathology
- 97.8% female
- 33.1 average hours per week
- 40.4 years – average age
- limited numbers of staff in regional and rural LHDs

Genomics landscape in NSW



May 2015
The NSW Genetic Counselling Workforce: Background Information Paper: an Evidence Check rapid review (brokered by the Sax Institute)

February 2017
The Changing Landscape of the Genetic Counselling Workforce (Urbis)

June 2017
NSW Health Genomic Strategy

2018
NSW Health Genomic Strategy: Implementation Plan 2018-2020

December 2019
Human Genetics Society of Australasia. Scope of Practice for Genetic Counsellors

2019
Establishment of Genetic Counsellor Advisory Group

2021

The vision for NSW Health genomics is that by 2025 NSW Health will be recognised as a leader in the development and use of appropriate genomic technologies in health care and public health for the benefit of the NSW population.

Workforce supply drivers

- Career opportunities: availability of: permanent positions, full-time positions, clear career pathways, new graduate positions
- Attraction of undergraduate students: cost of course, availability of supervision for students
- Workforce planning: numbers, distribution & succession planning
- Education & training opportunities

Workforce demand drivers

- Advancements in technology
- New policy drivers: mainstreaming of services
- Increased awareness and recognition of the profession
- Limited capability of other health professionals in genomics
- Increasing patient health literacy and expectations
- Increased research increasing demand for testing

Future opportunities

-  Define scope of practice and working at top of scope
-  Develop career pathways and supporting structures
-  Define role of support workforces including admin and intake officers
-  Expand use of technology to deliver services
-  Develop a strategy for integration with mainstream services

Actions for effective change

Undertake a state-wide workforce stocktake

Raise awareness of the profession in NSW

Develop key performance indicators

Engage the Advisory Group to drive opportunities

Background and approach

Background

The NSW Health Professionals Workforce Plan 2012-2022 (the Plan) requires the NSW Ministry of Health to develop workforce modelling projections to 2030 for the Allied Health workforces (recommendation 7.8). The Plan identifies small but critical workforces that require attention to meet the needs of a changing health care service in NSW.

A Horizons Scanning and Scenario Generation Project was undertaken by HealthConnect Consulting to identify the risks, issues and opportunities relating to the genetic counsellor workforce, including challenges and drivers that are expected to influence the profession over the next fifteen years. This is a report of the discussions, findings and key actions for effective workforce change from the project.

Approach

The project consisted of the following five key activities, in alignment with the NSW Ministry of Health Horizons Scanning and Scenario Generation methodology, to gather and synthesise information and test concepts:

Activity	Description	Date
Rapid literature review	A rapid literature review was conducted to present evidence and support the project activities. This was done as a rapid review, a form of evidence synthesis that is less comprehensive than a standard systematic review and conducted within a shorter time frame. (Attachment 1 presents the rapid literature review.)	December 2020
Stakeholder consultations	One-on-one interviews were conducted with a range of stakeholders including a clinical geneticist, genetic counsellors, university representatives and the Australian Genomics Health Alliance, with the objective of canvassing a broad and comprehensive range of information relevant to the genetic counsellor workforce.	February 2021
Horizons scanning workshop	The Genetic Counsellor Horizons Scanning workshop was designed to identify the current and future workforce supply and demand drivers, and the challenges and opportunities for the workforce. The workshop focused on the future vision for the workforce as well as value-based health care. Workshop participants included genetic counsellors from across NSW, representatives from Melbourne University and the University of Technology, Sydney and the Human Genetic Society of Australasia.	1 February 2021
Online survey	An online survey, was open to all NSW Health genetic counsellors. The purpose of the survey was to broadly assess the perceived impact on each workforce of the key drivers, challenges and opportunities identified through the literature review, consultations and Horizons Scanning Workshop.	February 2021
Scenario generation workshop	The purpose of the Scenario Generation workshop was to build upon the insights obtained from the survey and the outcomes of the Horizons Scanning Workshop. Workshop participants discussed plausible workforce scenarios considering workforce drivers and agreed trends; identified scenario related opportunities, risks and barriers; and determined potential impacts and priorities.	1 March 2021

Current state

Genetic counselling is a rapidly evolving, dynamic profession and the breadth and nature of professional practice within the profession of genetic counselling continues to expand.¹ There is considerable variation in role scope of genetic counsellors.

Although the application of genomic knowledge is transforming the way healthcare is being delivered and the types of roles for genetic counsellors expanding, the literature indicates the core skills of genetic counsellors are highly valued now and will remain critical into the future. Core genetic counselling skills are seen to have consistently supported the adaptation to advances in genetic technologies and practice demands. Genetic counsellors have specialised education in genetics and counselling.

Genetic counsellors work as part of a team in a range of settings including hospitals and community health centres, medical specialist clinics, obstetric ultrasound practices, research institutions, genetics laboratories and policy and project roles with government.

The rise of genomic medicine presents a major workforce development challenge for healthcare professions and organisations, including NSW Health. Making genetics and genomics an integral part of mainstream clinical practice will change this profoundly. The NSW Health Genomic Strategy Implementation Plan 2018-2020² prioritises identifying and describing the genomics workforce roles that are critical to current and anticipated future workforce demands and improving genomics education, of which genetic counsellors play a key role.

The NSW Health genetic counsellor workforce

In order to practice in Australia, a genetic counsellor must complete a clinical Masters of Genetic Counselling degree approved by the Board of Censors for Genetic Counselling (under the auspices of the Human Genetics Society of Australasia, HGSA³).

Following attainment of the relevant degree, a minimum of one year on-the-job training is required prior to starting the certification process which takes a minimum of three years to complete.

In 2020, the HGSA Board of Censors for Genetic Counselling was granted full National Alliance of Self-Regulating Health Professionals (NASRHP) membership for the regulation of genetic counsellors.

Figure 1: NSW Health workforce profile

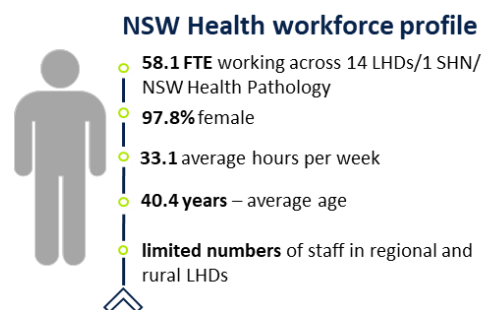


Figure 1 presents a high-level workforce profile of genetic counsellors employed by NSW Health.⁴

¹ Human Genetics Society of Australasia, December 2019

² <https://www.health.nsw.gov.au/services/Pages/genomics-implementation-plan.aspx>

³ <https://www.hgsa.org.au/>

⁴ Data referenced from NSW Ministry of Health

Online survey findings

There were 56 responses to the workforce survey. Most respondents (n=49) were from Local Health Districts/ Speciality Hospital Networks (LHD/ SHNs). Other respondents (n=7) included the private sector, university, people employed not as a genetic counsellor and people not employed (including new graduates).

93% of respondents were female, 5% were male and 2% preferred not to specify. Over 70% of respondents were under 44 years old (refer Figure 2). No respondents identified as Aboriginal or Torres Strait Islander. Most respondents intend to stay with NSW Health for the next 5 years (refer Figure 3).

Figure 2: Survey respondents by age

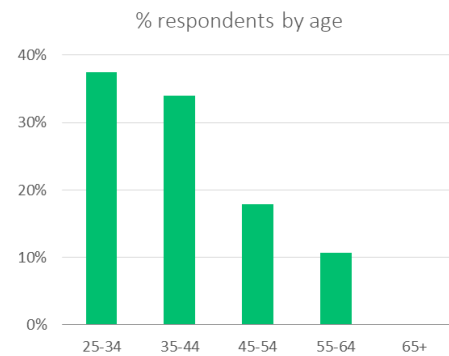
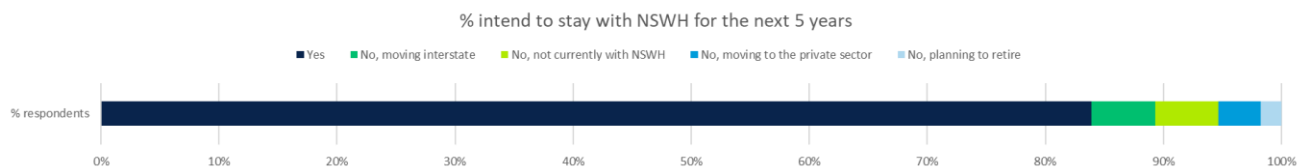


Figure 3: Survey respondents intending to stay at NSW Health for the next 5 years



Respondents typically had multiple qualifications, including post-graduate degrees (particularly Master's, post-graduate diploma or graduate diploma in genetic counselling). 75% of respondents are certified or working towards becoming certified (refer

Figure 4), and some referenced overseas certifications.

Figure 4: Certification status of respondents



Hours worked

Almost half of respondents work 30-40 hours per week and two thirds of respondents were satisfied with their number of hours worked (refer Figure 6). Most respondents work in ambulatory/outpatient settings, with two thirds of respondents working in multiple settings (44% in two settings, 12% in three settings, 10% in four settings). Rare diseases (62%), population health (54%) and cancer (36%) were the most common specialty areas (refer Figure 5). Additional areas included: general counselling, intellectual disability, neurocognitive conditions, infectious diseases, microbiome health, renal disease, amyloidosis specialist clinics, hypercholesterolaemia, non-rare genetic diseases, midwifery and genetics education.

Figure 6: Average weekly hours worked

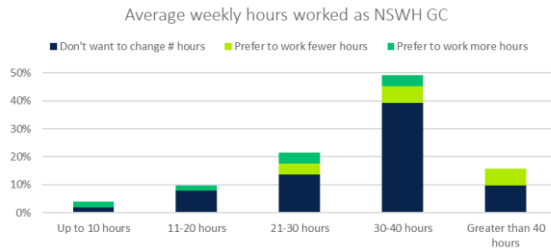
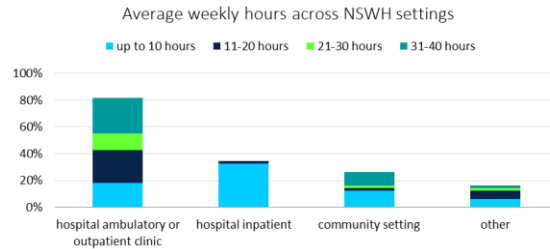


Figure 5: Average hours across settings



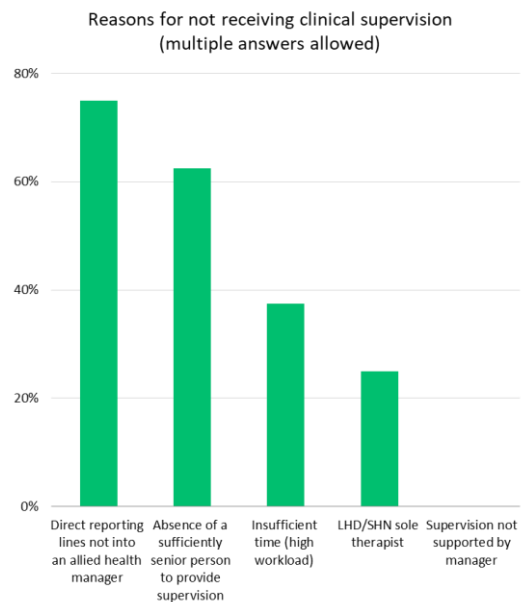
Clinical supervision

The purpose of clinical supervision⁵ is to ensure:

- delivery of high-quality patient care and treatment through accountable decision making and clinical practice
- facilitation of learning and professional development
- promotion of staff wellbeing by provision of support.

17% of respondents working in LHDs reported that they do not receive clinical supervision (refer Figure 7). The two most common reasons reported for not receiving clinical supervision are that direct reporting lines are not into an allied health manager and there is an absence of a sufficiently senior person to provide supervision. No respondent reported that supervision is not supported by their manager.

Figure 7: Reasons for not receiving clinical supervision



Genomics workforce functions

NSW Health has identified six core genomics functions across the patient journey. The genomic workforce will need to be equipped with capabilities to fulfil these functions into the future. Table 1 provides an overview of these functions.

Table 1: Genomics capabilities and role of genetic counsellors

Required genomics capabilities across the NSW Health workforce

⁵ Health Education and Training Institute 2012, The superguide: a handbook for supervising allied health professionals, HETI, Sydney

- Champion – provide advocacy for genomic testing
- Test – provide sequencing and testing services
- Assess – provide clinical assessments based on results from genomic testing
- Educate – provide advice and training to colleagues as well as educating patients
- Administrate – provide digital administration and protection of genomic data
- Govern – provide institutional leadership, governance and policy development

Role and scope of practice of Genetic Counsellors

A summary of the current role of genetic counsellors within NSW Health is presented below:

- Provide specialist knowledge in human genetics, counselling and health communication skills.
- Provide information to individuals and families about genetic conditions, which may involve education about conditions that are inherited or who in the family may be at risk of developing a particular condition.
- Provide emotional and practical support to help people adjust to living with, or being at risk for, a genetic condition.
- Work as part of a multidisciplinary team (MDT) in a range of settings including hospitals and community health centres, medical specialist clinics, obstetric ultrasound practices, research institutions, genetics laboratories and policy and project roles with government.

Future scope of practice

The Urbis report⁶ (2017) suggests there are opportunities to expand the role and activity of genetic counselling. Opportunities cited include:

- Expand the role and activity of genetic counsellors.
- Core skills are highly valued now and will remain critical into the future: specialist knowledge, communication, counselling and psychosocial assessment.
- Develop new and innovative ways of counselling and communicating with patients and professionals.
- Genetic counselling positions within non-genetics services (e.g. cardiac and neuroendocrine clinics) or private clinics.
- Culturally appropriate genetic counselling services.
- Development of a primary care genetic counselling model, in which GPs are responsible for communication (and associated counselling) of basic test results, and a part-time onsite genetic counsellor takes on more complicated cases.
- International trends: employment within mainstream health care services in order to facilitate ethical and appropriate genetic testing; employment in laboratory settings and involvement in variant curation.

Emerging challenges

The speed and trajectory of the technology advances in genomics presents unique challenges. Large-scale sequencing is now possible, cost of testing is lower and with the availability of high-speed computing to support sophisticated analysis, it is feasible for genomics to become a part of routine healthcare. This is compounded by rising consumer interest in, and demand for, genomic services, as well as the increasing availability of tests being offered by providers. The Urbis report (2017) outlined emerging challenges for the genetic counselling workforce based on the literature and stakeholder input, these include:

- Workforce development challenges: current and future roles.
- The transition from genetic counsellor to 'genomic counsellor'.
- Matching supply and demand for genetic counselling services.

⁶ Kurti, L., Tomiczek, C., Brophy, E., & Fase, D. (2017). The Changing Landscape of the Genetic Counselling Workforce: Final Report. NSW: Urbis.

- Health profession registration and education pathways.
- Variation across NSW Health in clinical governance and supervisory arrangements.
- Potential rise in Direct-to-Consumer Private Genetic Testing (DTCGT) services.
- Integration with mainstream health services, workforce capability and genomics education.
- Insurance implications for consumers.

Genomics in NSW

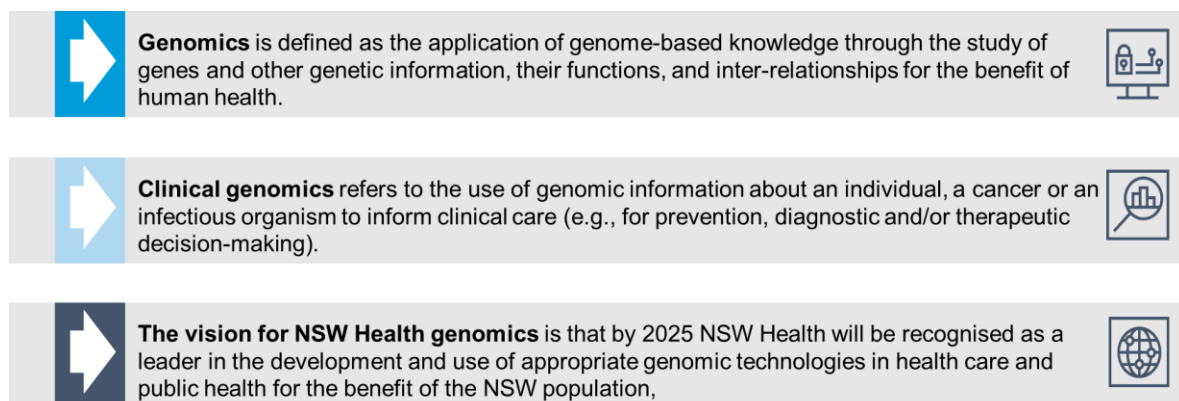
Successful implementation of genomic technology relies on whole-of-system change. Genomic medicine promises better patient outcomes and a more efficient health system through rapid diagnosis, early intervention, prevention and targeted therapy. NSW Health recognises that integrating genomics into the NSW health system will improve the health of the people of NSW, both at an individual and population health level.

The NSW Health Genomics Strategy is the beginning of a long-term commitment NSW Health is making to ensure the potential benefits of genomics are incorporated into the NSW Health system effectively and efficiently. This Strategy seeks to bring together the key genomics policy issues and proposes a way forward to address the choices and challenges that we may face in this fast-evolving area of healthcare.⁷

The NSW Health Genomics Strategy outlines the definitions of genomics and clinical genomics together with the vision for NSW Health genomics as presented in

Figure 8. Workforce planning and training for genomics are among the strategies to achieve the NSW Health vision.

Figure 8: Definitions of genomics



⁷ NSW Ministry of Health. (2017). NSW Health Genomics Strategy.

Figure 9: Timeline for genomics in NSW Health



It is anticipated that new genomic technology will transform patient care in the areas of cancer, rare disease, population health, infectious disease, and microbiome. This is expected to have a significant impact on patient care across the patient journey.

Figure 9 presents a high-level timeline of the key genomics and genetic counsellor related work undertaken by NSW Health in the past five years.

The terminology ‘mainstreaming’ is frequently used and in this context means that where appropriate, incorporating genomics into existing clinical services and pathways and into service models that are existing, emerging and new.

Setting the scene

Value based healthcare and the workforce

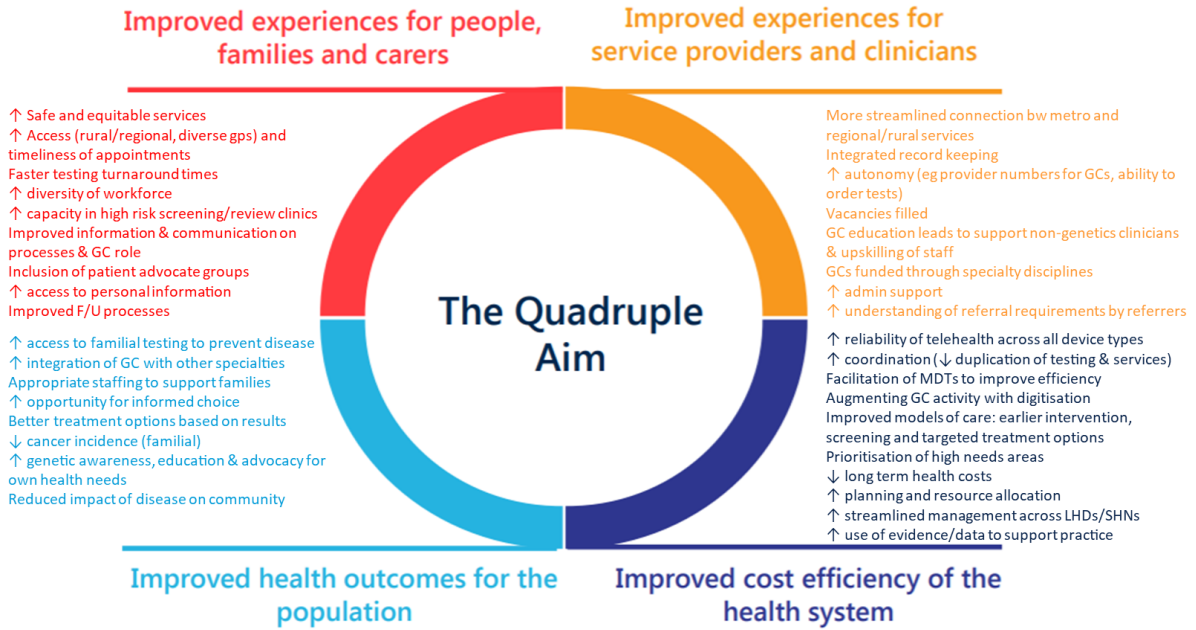
Value based healthcare will improve health outcomes that matter to patients by evolving how patients receive and how clinicians provide care.⁸ Value based healthcare in NSW means delivering services that improve:

- the health outcomes that matter to patients
- the experience of receiving care
- the experience of providing care
- the effectiveness and efficiency of care.

The Quadruple Aim is the contemporary framework underpinning best practice health service planning, design and implementation. The fundamental premise of the framework is that value is harnessed through simultaneously improving population health, improving the experience of receiving and providing care, and of reducing per capita cost. Figure 10 illustrates what value-based health care means from a genetic counsellor workforce perspective across the four quadrants of the Quadruple Aim.

Figure 10: Value based care for the genetic counsellor workforce

⁸ Koff, Elizabeth and Lyons, Nigel. (2020). Implementing value-based health care at scale: the NSW experience. Med J Aust 2020; 212 (3). doi: 10.5694/mja2.50470. Published online: 17 February 2020.



Vision for the genetic counsellor workforce

For the purpose of this project, a shared vision for the NSW Health Genetic Counsellor workforce was defined at the first workshop. The vision provides a foundation to discuss the current workforce and to guide future workforce priorities.

NSW Genetic Counsellor Workforce Vision 2030

A strong and valued workforce operating at full scope of practice, in collaboration with health professionals across all specialties, enabled to provide timely and equitable services to the population.

The core elements of the vision are further defined below:

Strong and valued workforce: adequate numbers and diversity of the workforce; clear identity and role understood and valued by a wide range of health professionals and the community.

Full scope of practice: Genetic counsellors operating at full scope of practice; developing new models of care to support new ways to work; utilising technology and efficient data systems.

Collaboration with health professionals: integrated across relevant clinical specialties and embedded MDTs; linked with hospital, community and primary care clinicians; supporting mainstream clinicians to deliver genomic related care as appropriate.

Enabled: structured career pathways; appropriate governance; capacity for mentoring/supervision; streamlined workforce planning and resource allocation (including students, new graduates and experienced genetic counsellors).

Timely and equitable service: prioritised based on population need.

Population: covering all age groups with services tailored to meet individual needs (diversity and location) informing the population to minimise illness and/or passing on of illness.

Supply and demand drivers

Supply drivers

Supply drivers encompass the factors likely to influence the supply of genetic counsellors to the workforce. An adequate number and equitable distribution of genetic counsellors is essential to ensure the availability of appropriate genetic counselling services across NSW. Supply drivers that might be expected to influence the role of the genetic counsellor workforce now and in the future were identified through consultation, the online survey and workshops. Supply drivers reported below have not been verified against any data. These have been grouped into four themes:

1. Career opportunities

- The availability of fulltime positions in the public sector for genetic counsellors was reported to be limited. Many genetic counsellors, particularly new graduates, are seeking full time positions. Similarly, it was reported that not all positions were permanent and a mix of contract and soft funding (positions funded through trust funds, research funding etc) positions were common. Furthermore, the number of fulltime positions in the private sector was thought to be increasing.
- There are currently no designated positions for new graduate genetic counsellors or genetic counsellor intern positions within NSW Health. Stakeholders considered these types of positions as valuable in growing the workforce and in providing new graduates/trainees with support and mentoring during their first year of practice. Creating these types of positions was seen as an important recruitment strategy that could be implemented at the local level.
- The number of genetic counsellors operating in rural and regional areas could also be expanded through the utilisation of virtual care and benefit from the lessons learned and growth in the use of virtual care during COVID-19 pandemic.
- Career pathways and career progression for genetic counsellors in NSW Health were reported to be limited. It was noted that some senior genetic counsellors were undertaking PhD studies and subsequently would be looking for research roles. There may be an opportunity to identify a research career pathway for individuals to retain more senior genetic counsellors and at the same time support supervision requirements. Additionally, consideration of roles such as clinical educators and supervisors may be another solution to enhancing career pathways and progression for genetic counsellors.

2. Attraction of undergraduate students

- Genetic counsellors are qualified through a master's degree which includes student clinical placement time, currently available through the University of Technology Sydney (UTS) (with 24 student places per year) and the University of Melbourne (UniMelb) (with 20 student places per year as at 2021). A reduced number of graduates from both UTS and UniMelb in recent years due to low numbers of student clinical placement opportunities was identified as potentially impacting supply of genetic counsellors, however graduate numbers were now reported to be steady again. It was also suggested that the universities had capacity to train more genetic counsellors however places were currently limited due to the availability of clinical placements.
- The availability of clinical placements for students was reported to be a current challenge. It was suggested that there are not currently enough experienced/senior genetic counsellors with sufficient time to provide supervision to students.
- It was suggested that the cost of the master's course may be prohibitive to some students, particularly those from more diverse, disadvantaged and/or low socio-economic backgrounds. It is also to be noted that the access to a master's degree may be difficult for mature students with additional financial and social responsibilities. There is currently no Commonwealth scholarship supported places for the master's degree.

This may be an area for education providers to pursue in the future to attract a more diverse group of students.

3. Workforce planning

- Workforce planning is a foundational component to ensure NSW Health trains, recruits and retains a fit-for-purpose workforce to effectively meet demand and the needs of the community. The genetic counsellor workforce has an established advisory network, an ideal vehicle to support state-wide collaboration and workforce planning and consider needs across all LHDs/SHNs.
- In-line with the mainstreaming of genomics in NSW Health, the involvement of other hospital sub-specialties in workforce planning may also be beneficial. Genetic counsellors are becoming more integrated and embedded across multidisciplinary teams and there may be opportunity for genetic counsellor positions to be partly funded through other specialist areas utilising their skills in MDTs.
- It was suggested that succession planning to meet workforce needs in future years is critical given the small size of the workforce, limited training pipeline and the growth in demand for genomic and genetic services.
- Improving data and information about the workforce and activity will support workforce planning and the sustainable supply of the workforce.

4. Professional development and training

- There is an ongoing requirement for genetic counsellors to participate in professional development as genomics rapidly evolves and to maintain certification.
- The availability of clinical supervision for genetic counsellors working towards certification was reported to be a challenge. The supervision of non-certified genetic counsellors is an area for consideration.

Survey findings

Survey respondents were asked to rate the impact of supply drivers. The survey showed that career opportunities, and attraction of undergraduate student drivers were rated higher than other drivers. Over 80% of respondents rated all drivers as having significant or some impact, except *education and training* drivers, as illustrated in **Error! Reference source not found.** Loss of mid-career and senior genetic counsellors (for example to PhDs) was a supply driver noted to impact the junior nature of the workforce and opportunities for clinical supervision.

Table 2 summarises the potential supply driver inputs to future workforce modelling.

Figure 11: Key workforce supply drivers and impact

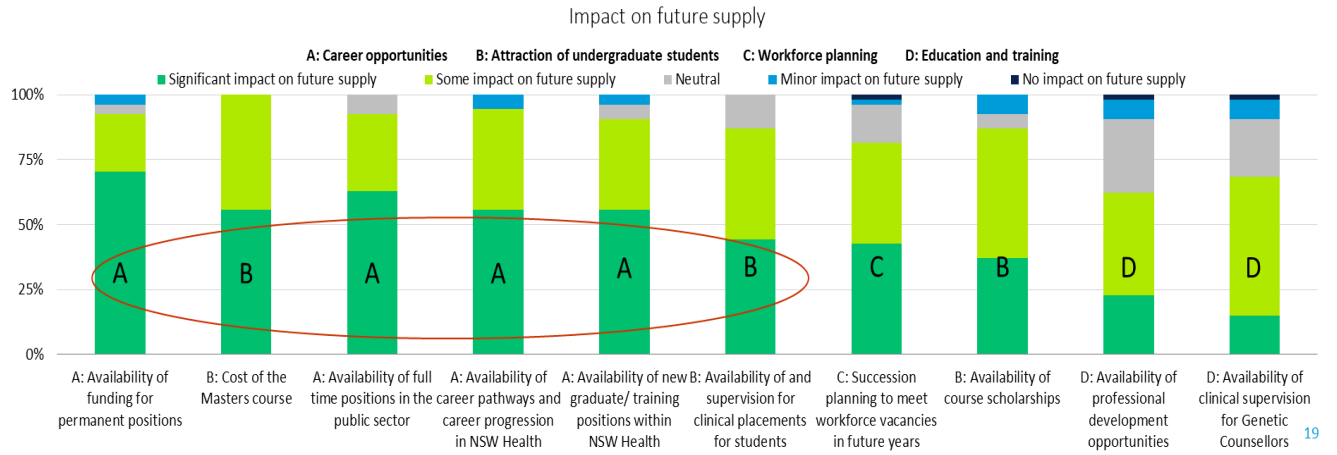



Table 2: Inputs to workforce modelling

 Inputs to future workforce modelling – supply drivers
<ul style="list-style-type: none"> • UTS and UniMelb Masters of Genetic Counselling course graduating numbers, intake numbers and projections, proportion of graduates staying in NSW for work • Workforce data from NSW State-wide Management Reporting Service (SMRS) (sourced directly from the NSW Health HR and Payroll System StaffLink). SMRS provides the ability for users to look at workforce information at an organisational level as well as cost centre level and is used to support workforce operations and planning. • NSW Health clinical placements for genetic counsellors • Trends in job advertisements for genetic counsellors by sector, location, and part-time/full-time

Demand drivers

Demand drivers encompass those factors likely to influence the demand for genetic counsellor services. Key demand drivers that might be expected to influence the role of the genetic counsellor workforce now and in the future have been identified. The demand drivers have been grouped into six themes:

1. Technology

- Advancements in genomic technology and increased use of technology for screening, therapeutics, predictive and diagnostic purposes is continually growing and is placing a greater demand on the genetic counsellor workforce. For example, the increased use of cascade testing, involving the testing for gene changes in individuals at risk of a genetic condition that was previously identified in a family member. As testing is integrated into mainstream services, genetic counsellors are working across more diverse areas to meet the demand of patients and families requiring genetic counselling services.
- Advancements in population-wide screening, cheaper and more effective diagnosis and more targeted treatments will all increase demand for genetic counselling services.
- Genetic counsellors are best placed to utilise their expertise to manage patients and families with the most complex requirements such as a pathogenic or uncertain variant.

2. Health system influencers

- NSW Health has a strategic vision to be recognised as a leader in the development and use of appropriate genomic technologies in health care and public health for the benefit of the NSW population. Significant work has been undertaken in the past five years including the publication of the NSW Health Genomic Strategy and accompanying implementation plans.
- The goal of mainstreaming genomics and the rapid growth of genomics is a challenge for genetic counsellors. However significant opportunity exists to embrace the change and for genetic counsellors to be key multidisciplinary team members in this emerging environment.

3. Awareness and recognition

- Increased awareness, recognition and perceived value of the profession by other specialties has been growing, mostly due to dedicated professionals promoting their role and the evolution of genomics.
- Opportunity exists for genetic counsellors to actively promote their scope of practice, knowledge and important contribution to genomics and patient care as distinct from other disciplines.

4. Health system capability

- The NSW Health workforce (across many different professions) will need to be equipped with capabilities required to fulfil the key genomics functions required to successfully mainstream genomics services.
- Stakeholders indicated that there are currently a limited number of other health professionals trained and capable in genetic testing implications.
- It was identified that not all trained health professionals were either confident or willing to work in genomics.

- Maintaining and building strong relationships with other professionals fulfilling these roles will be critical for the genetic counsellor workforce and to leverage these capabilities to their fullest advantage.
- The opportunity to expand genetic counsellor scope of practice could support future system capability.

5. Patient trends and expectations

- The NSW population is projected to grow by 14% over the next 10 years⁹.
- Patients are increasing their health literate in genomics, precision medicine and direct-to-consumer genetic testing. Increasing patient expectations and information requirements are impacting demand for services.
- Genomics has the potential to impact patient care across the patient journey, starting with better prediction of conditions through to treatment and survivorship. These advances will further prioritise the requirements for genetic counselling services where people are living longer and more informed and genetic counselling to patients and their families will be required.
- There exists opportunity to upskill other health professionals where appropriate to interact with patients to provide information, education and support informed choices.

6. Research

- The growth in genomic research and subsequent translational research was reported to be increasing demand and referrals to genetic counselling services.
- The further development of clearly defined referral criteria and triage systems across the state will support genetic counsellors to prioritise patients and refer appropriate patients to research and clinical trials.

Survey findings

Survey respondents were asked to rate the impact of demand drivers as presented in Figure 12 **Error! Reference source not found.** Advancements and increased use of technology was the top-rated driver with over 85% of respondents rating it as having significant impact. Over 85% of respondents rated all drivers as having significant or some impact, except for patient trends and expectations: people living longer, survivor care and implications for families.

⁹ Population projections based on data from the NSW Department of Planning and Environment (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health.

Table 3 summarises the potential demand driver inputs to future workforce modelling.

Figure 12: Key demand drivers and impact

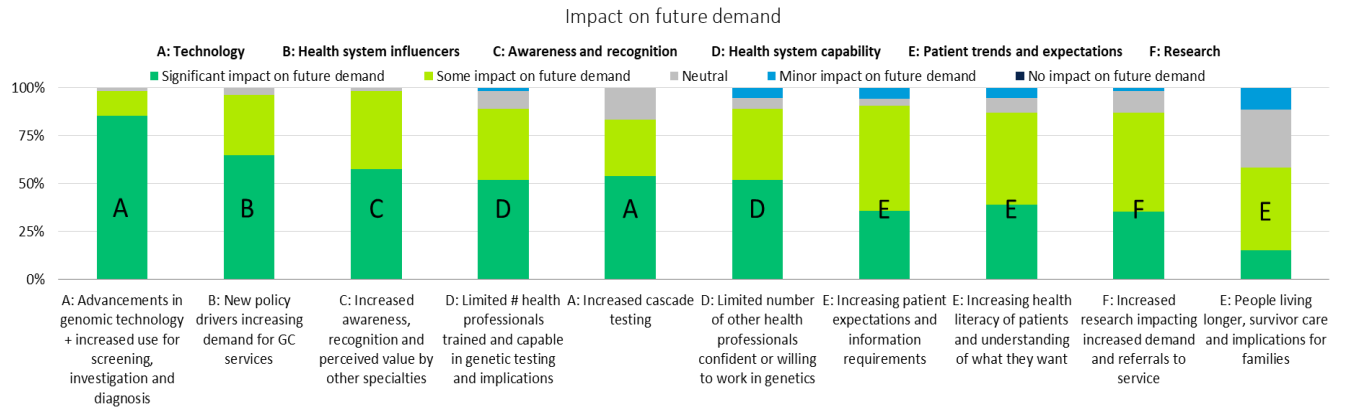



Table 3: Demand driver inputs to future workforce modelling

	Demand driver inputs to future workforce modelling
	<ul style="list-style-type: none"> • Census and demographic data • Population projections across all age groups and LHDs/SHNs • Demand projections across specific conditions e.g. cancer, family planning, rare diseases etc • Aboriginality status and prevalence of genomic conditions • Numbers and trends of relevant MDT in NSW Health that genetic counsellors could add value to • Referral numbers and sources • Place of residence of patients to identify demand for genetic counsellors in LHDs/SHNs • Average waiting time for appointments • Expected advances in technology and how these may reshape the genetic counsellor role and related roles • Average caseload and time spent on different tasks (clinical, admin, etc) by genetic counsellors and how these would change due to new policy drivers or a change in the workforce mix • Consider the genetic counsellor workforce in the context of supporting roles (e.g. admin and intake roles) that will support genetic counsellors to work at full scope of practice

Challenges

Other challenges, outside those related to supply and demand drivers, were highlighted by the workforce during consultation. These challenges are summarised under the following four themes:

1. Workforce support structures

- Governance arrangements provide professional support for the workforce. Variation across LHDs/SHNs in operational and clinical governance was emphasised. Some genetic counsellors reported to allied health while others reported through the genetics service. Operational and professional reporting lines were often different.
- It was acknowledged that regardless of formal reporting lines, it is crucial that genetic counsellors are linked with other allied health professionals and management. Solo genetic counsellors in particular reported feeling isolated and unknown to Directors of Allied Health.
- Formalised and clear governance structures are required to ensure the workforce is well supported by management and actively included in the broader allied health workforce. Appropriate local governance arrangements will also support workforce planning on an ongoing basis and the implementation of any actions required to support workforce priorities.
- Supervision challenges were highlighted under supply drivers earlier in this report.

2. Availability and use of data

- Local data systems were reported to be fragmented in nature and often required duplication across systems. Capture of local activity data was noted as an area for improvement, the need for more streamlined clinical records management to enhance efficiency was also highlighted.
- Accurate statewide data specific to the genetic counsellor workforce was also noted as an area for improvement.
- Access to detailed data and analytics provides the basis for understanding current and future workforce requirements. Improved information about the genetic counsellor workforce, including by the LHDs/SHN, will support workforce planning and the sustainable supply of the workforce into the future as new and contemporary models of care are implemented. Accurate data will support distribution of the workforce and support service delivery in more efficient and effective ways.
- Workforce data can be a powerful tool to raise awareness and to demonstrate the value of genetic counsellors.

- Genetic counsellor workforce data should also be considered in the context of the broader workforce providing genomic services, that is of genomic medicine stakeholders (existing genetic services, clinical geneticists, cancer geneticists, prenatal genetic services, reproductive genomics) and non-genomic medicine stakeholders (non-genetic health providers, primary care, specialists, allied health, nursing, midwifery etc).

3. Professional identity and career pathways

- The professional identity of genetic counsellors was noted to be an ongoing challenge. This challenge also relates to the overarching awareness and recognition of the profession which in turn impacts both supply and demand.
- Linkages with the LHDs/SHNs Director of Allied Health was important both in terms of advocacy for the profession and to raise awareness of the profession.
- As other specialties build new capability to support the mainstreaming of genomics it will be important for the genetic counsellor workforce to evolve and clearly define their role and scope of practice.
- Genetic counsellors agreed that there was opportunity to streamline current practices and raise awareness across other workforces.
- Career pathways has been highlighted earlier in this report under supply drivers.

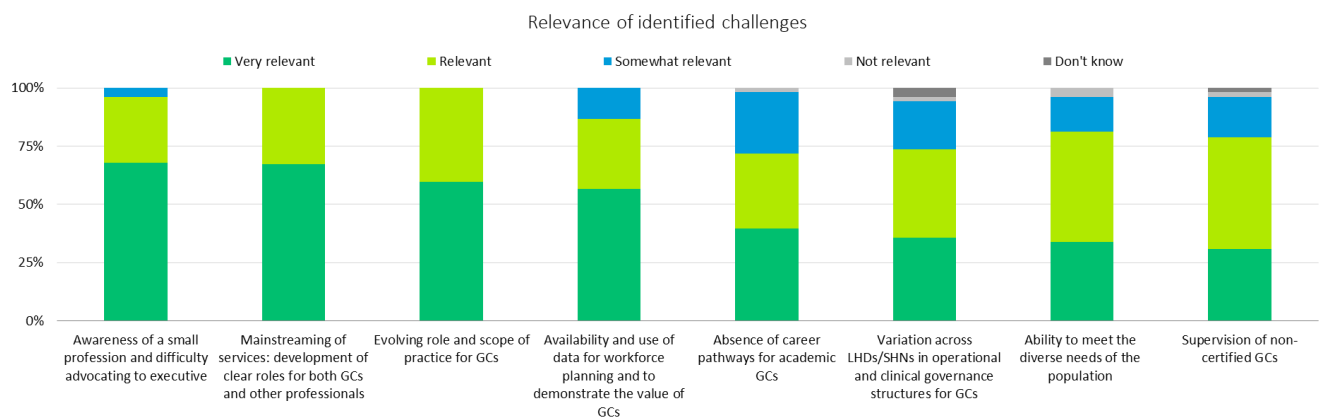
4. Diverse population needs

- Ensuring equality of access to genetic counselling services in NSW was reported to be a challenge. This includes (but is not limited to) providing services to the Aboriginal population, people with a disability, Culturally and Linguistically Diverse (CALD) groups and rural and regional populations.
- Just over a quarter of the people in NSW live outside the three major cities of Sydney, Newcastle and Wollongong. Available data highlights that there are a limited number of genetic counsellors working in rural and regional areas trying to cover a vast population.
- There are no genetic counsellors employed by NSW Health identifying as Aboriginal.
- The genetic counsellor workforce highlighted the need to grow a more diverse workforce to meet the needs of the NSW population.

Survey findings

96-100% of respondents consider awareness, mainstreaming of services and the evolving role and scope of practice to be relevant or very relevant challenges. Challenges were ranked in order of significance as illustrated in Figure 13. **Error! Reference source not found.** Opportunities to address these challenges are discussed in the next section of this report.

Figure 13: Relevance of identified challenges



Opportunities for the future

Overview

A range of opportunities for the genetic counsellor workforce were identified throughout the project. Opportunities were considered in the context of the future workforce and three plausible scenarios were generated for discussion. Within each scenario, workforce enablers describe the components that support a particular scenario and include workforce planning, governance structures, education and professional development, raising awareness of the profession, data and evidence, and growth of the workforce. It is important to acknowledge that no one scenario or workforce enabler sits in isolation. Rather, elements are mutually dependent to support the future workforce, improve the patient journey and achieve the desired outcomes.

Scenario generation

Workshop participants were asked to consider the three scenarios below to stimulate thinking about the future workforce, considering supply and demand drivers along with challenges and opportunities.

- Scenario 1: Genetic Counsellors working at top of scope of practice and leveraging other workforces
- Scenario 2: Defined career pathways, governance structures and succession planning for genetic counsellors
- Scenario 3: Streamlined models for integration of genetic counsellors with mainstream services

These scenarios were informed by the literature review, outcomes from the consultations, the online survey, and the horizons scanning workshop.

While the scenarios presented here provide an overarching direction for workforce modelling, their components require further discussion and development prior to being operationalised across NSW Health. It is important to note that these are not the only possible scenarios and further work will determine the which opportunities the genetic counsellor workforce will take forward.

Scenario 1: Genetic Counsellors working at top of scope of practice and leveraging other workforces

Context:

- Clear role delineation and defining the scope of practice for genetic counsellors was identified as a significant opportunity for the workforce.
- The full scope of practice of a profession includes the full spectrum of roles, functions, responsibilities, activities and decision-making capacity that individuals within that profession are educated, competent and authorised to perform. The full scope of a profession is set by professional standards and in some cases legislation¹⁰. Working to full scope means working to the full extent of a genetic counsellors recognised skill base and/or regulatory guidelines, acknowledging that some functions may be shared with other workforces.
- A defined and consistent scope of practice will support contemporary models of care and keep pace with rising demand.
- It was identified that genetic counsellors often find themselves undertaking low value tasks such as intake and administration. Leveraging other workforces to undertake nominated tasks could support genetic counsellors to participate in more valuable activities. Opportunities exist to standardise and implement administration and intake services for genetic counselling in NSW Health. A core objective could be to provide support to all genetic counsellors across the state and to improve access and wait times for genetic counselling services by leveraging these other workforces including (but not limited to) administration and intake officers.

¹⁰ <https://www.health.qld.gov.au/ahwac/html/full-scope>

- Clinical work is important for genetic counsellors; however, this often means that other activities like research, continuing education, clinical supervision and progression of the profession are deprioritised. Leveraging other workforces to undertake nominated tasks could support genetic counsellors to participate in valuable non-clinical activities.
- The role of genomic medicine workforces (clinical geneticists, cancer geneticists, prenatal genetic services, reproductive genomics) and non-genomic medicine stakeholders (non-genetic health providers, primary care, specialists, allied health, nursing, midwifery etc) are other considerations in defining the scope of practice for genetic counsellors.
- New workforces such as those qualified through the Master of Health and Genomics (UniMelb) are also emerging.

Scenario 1: Genetic Counsellors working at the top of scope of practice and leveraging other workforces

It is 2030, and the system for delivering genetic counselling services in NSW has changed dramatically. Genetic counsellors are working at the top of their practice scope to provide greatest value to the system, patients and other health professionals.

Other workforces are providing valuable assistance to genetic counsellors in administration and intake roles, freeing up genetic counsellors to spend more time on more highly skills practices to meet demand and reduce waiting lists, and to participate in non-clinical activities.

This scenario has led to dramatic improvements in the patient journey, quality of care, access to care and many other outcomes.

Describe how this scenario works in 2030. How will the workforce implement this scenario?

1. Clearly define the role and scope of practice for genetic counsellors.

- Develop a standardised role and scope of practice for NSW Health genetic counsellors.
- The workshop suggested that genetic counsellors would like to work towards having provider numbers. However, it was unclear as to whether this would be achievable or the potential broader implications (eg medico-legal implications).

2. Leverage other workforces to enable genetic counsellors to work at top of scope

- Clearly define supporting workforce roles, including administration and intake assistants, to undertake designated tasks, considering the appropriate skill set and full time equivalent required.
- Develop a business case for the position of intake officer including evidence to demonstrate the benefits of an intake officer to the system and patients.
- Define what working at 'top of scope' means for the genetic counsellor workforce.
- Codesign workforce models that support genetic counsellors working at the top of scope, in collaboration with the NSW Ministry of Health and Agency for Clinical Innovation.
- Investigate the practicality of embedding genetic counsellor students in all genetic services to support the genetic counsellor workforce and grow the workforce.
- Investigate options to support genetic counsellors with administrative tasks.

3. Advocate and promote involvement of genetic counsellors in a wide range of service delivery

- Consider strategies to link genetic counsellors and collaborate more with other specialities.
- Utilise collaboration opportunities to educate other professions on the role, the defined scope of practice and value of genetic counsellors.
- Engage Australian Society of Genetic Counsellors (ASGC) in advocacy and promotion.
- Develop resources to support education of other professions that can be shared across the state.

4. Support confidence and consistent application of medico-legal parameters across the state

- Utilise the Genetic Counsellor Advisory Network to investigate the medico-legal context of genetic counsellor roles and responsibilities. Communicate findings across the state.

5. Improve data and record systems

- Enhance accurate and consistent recording of activity that meets minimum reporting requirements, and will support requests for funding and demonstrate value of the profession.
- Agree a consistent clinical records management and practices.
- Provide advice on statewide genomics systems for data management.
- Investigate options to support genetic counsellors with data management.

What are the potential benefits?

- Leveraging other workforces may enable genetic counsellors to work at top of scope and be better able to meet patient demand. This may also provide opportunity for more genetic counsellors to participate in research and supervision of students and junior clinicians.
- Improved genetic counsellor responsibility/involvement in the test ordering process
- Superior data quality and usefulness of data in workforce planning through improved consistency of collection

Scenario 2: Defined career pathways, governance structures and succession planning for genetic counsellors

Context:

- Professional roles are continually evolving and need to support new and future models of care and service delivery.
- Career pathways and opportunities for career progression for genetic counsellors in NSW Health are reported by stakeholders to be limited. The perceived absence of career pathways was thought to be directly related to the limited retention of experience genetic counsellors.
- Understanding the stage of training (new graduate, non-certified, certified) and areas of expertise (eg cancer, general genetics, prenatal, etc) are important factors to consider in determining career pathways.
- Formalised and clear governance structures are required to ensure the genetic counsellor workforce is well supported by management and supervision and training requirements for students, non-certified genetic counsellors and senior genetic counsellors are supported. It was suggested that there are not currently enough experienced/senior genetic counsellors with sufficient time to provide supervision to students and non-certified genetic counsellors.
- There may be an opportunity to identify a research career pathway within NSW Health to retain more senior genetic counsellors and at the same time support supervision requirements. Additionally, consideration of roles such as clinical educators and supervisors may be another solution to enhancing career pathways and progression for genetic counsellors.
- Succession planning to meet workforce vacancies in future years is required and the upskilling/mentoring of younger genetic counsellors and graduates is a priority.

Scenario 2: Defined career pathways, governance structures and succession planning for genetic counsellors

It is 2030, and the system for delivering genetic counselling services in NSW has changed dramatically. Defined genetic counsellor career pathways have been established and provide structure and a mechanism to meet supervision requirements, support retention of genetic counsellors and enable succession planning for the future.

This scenario has led to dramatic improvements in the patient journey, quality of care, access to care and many other outcomes.

Describe how this scenario works in 2030.

1. Clearly define and implement governance structures for genetic counsellors

- Develop a governance structure encompassing genetic counsellors operating across all levels of experience including students, new graduates, non-certified, certified and senior genetic counsellors.
- Align governance structures and career pathways with the classification of health professional positions as per the NSW Health Services Health Professionals (State) Award 2019¹¹ and identify opportunities for genetic counsellors to progress to higher levels.
- Identify any award constraints and liaise with the Ministry's Workplace Relations Branch about the feasibility of changes to address any issues.
- Establish and/or strengthen discipline specific reporting lines through to Director of Allied Health

¹¹ <https://www.health.nsw.gov.au/careers/conditions/Awards/health-professional.pdf>

- Link with ASGC in their project to address supervision. The ASGC supervision project aims to use the benefits of Zoom to create online supervision networks. It is anticipated that this will be launched mid-2021.

2. Identify available career pathways and opportunities for progression

- Develop standardised protocols and policies across all LHDs/SHNs to support consistency and transparency in career progression.
- Engage with the Advisory Network to draft position descriptions for different levels of genetic counsellor managerial role.
- Investigate a standardised system to support development of genetic counsellor career pathways. Career pathway options may include clinical/research/education roles.
- Establish a process for succession planning linked to career progression.
- Support Level 2 genetic counsellors to supervise students, develop supervision skills and establish evidence for career progression.
- Enhance relationships and connection with Directors of Allied Health to ensure information relevant to career pathways is received.
- Investigate opportunities for funding to support training and professional development. Potential funding sources may include the NSW Health HETI Workplace Learning Grants for allied health professionals, NSW Rural Allied Health Post Graduate Scholarship.

What are the potential benefits?

- Defined career pathways and improve opportunities for career progression
- Clear operational supervision and governance structures
- Satisfied workforce and improved retention
- High quality clinical care for clients and families including equitable care across the state regardless of where people live

What are the challenges/risks?

- Potential difficulty moving above level 2 and/or level 3 per the Health Professional's award
- Separating genetic counsellor model from geneticist model
- Burden of administration that makes it difficult to build a body of evidence to progress

Scenario 3: Streamlined models for integration of genetic counsellors with mainstream services

Context:

- Employing an MDT approach is best practice across a wide range of health care conditions and NSW Health genetic counsellors currently work across many MDTs.
- The roles of clinicians from other disciplines are important considerations as we move towards mainstreaming of genomics.
- Genetic counsellors are becoming more integrated and embedded across MDTs and there may be opportunity for additional positions supported through other specialties, for example administration or intake roles.
- The NSW Health workforce (across many different professions) will need to be equipped with capabilities required to fulfil the key genomics functions required to successfully mainstream genomics services. Stakeholders indicated that there are currently a limited number of other health professionals trained and capable in the management of genetic testing implications.
- It was also identified that not all trained health professionals trained in genetics were either confident or willing to work in genetics.
- Maintaining and building strong relationships with other professionals fulfilling these roles will be critical for the genetic counsellor workforce and to leverage these capabilities to their fullest advantage.
- Some Australian Genomics research suggests there could be value in including education for genetic counsellors in how to participate in MDTs early in their education/career to increase confidence in contributing to discussions.

Scenario 3: Streamlined models for integration of genetic counsellors with mainstream services

It is 2030, and the system for delivering genetic counselling services in NSW has changed dramatically. Genetic counsellors are key members of multidisciplinary and specialist teams.

Genetic counsellors are providing valuable specialist input to other specialties, building capacity and supporting all specialties with the most complex patients.

This scenario has led to dramatic improvements in the patient journey, quality of care, access to care and many other outcomes.

Describe how this scenario works in 2030. How will the workforce implement this scenario?

1. Grow awareness and trust across other specialties

- Identify strategies to support consistent presence across other specialties to build trust and acceptance.
- Support genetic counsellors to be 'experts' in identified specialty areas through training relevant to mainstreaming. Training models may include central hub training, specialist unit training.
- Develop resources to support upskilling of other professions (eg Junior Medical Officers) for mainstreaming
- Utilise research and examples of established MDTs from other specialties to demonstrate the value of genetic counsellors.

2. Define the genetic counsellor role and scope of practice specific to mainstreaming

- Define role and scope of practice for genetic counsellors in multidisciplinary team meetings/clinics.

3. Define specific needs of rural and remote services

- Identify different requirements across different settings and locations, for example the experience of regional and central units is very different (may need different models to incorporate mainstreaming)
- The level of engagement of some specialties is minimal in some outreach settings as they are time poor – Investigate how best to engage these teams.

4. Collaborate with other specialist teams and identify their needs

- Build relationships and promote awareness and value across other health professions/specialties.
- Communicate scope of practice and value of genetic counsellors and determine what other specialist teams require from genetic counsellors.
- Investigate strategies to encourage other medical specialties to include and fund genetic counsellors in their services.
- Investigate creation of 'genetic counsellor education leads' (attached to genetic services) to work with other services and upskill teams.

5. Define outcome measures to demonstrate value across the quadruple aim

- Establish a working group consisting of genetic counsellors and geneticists to determine outcome measures, particularly linked to mainstreaming.
- Identify high priority value-based care outcomes for measurement, for example patient experience, patient outcomes, system outcomes.
- Compare cost of genetic counsellors to other professionals to demonstrate value and return on investment.
- Multiple papers and examples of defining outcomes were highlighted in the workshop.^{12,13,14}

What are the potential benefits?

- Only seeing patients that you need to see (reduce waiting lists and thereby improve patient experience)
- Considered a reliable expert resource / of which others come for trusted advice
- Education and awareness
- Right test/right advice and better outcomes may improve patient experience
- Maximising limited resources

What are the challenges/risks?

- Training of genetic counsellors in specialty services
- Time and resources for genetic services to support mainstreaming
- Broader awareness of what Genetic Counsellors do and how they add value
- Risk – unsupported genetic counsellor staff embedded in other teams working outside their scope (this needs clinical governance)
- Support for new graduates in MDT work

¹² <https://ascopubs.org/doi/abs/10.1200/OP.20.00464>

¹³ <https://onlinelibrary.wiley.com/doi/abs/10.1002/jgc4.1352>

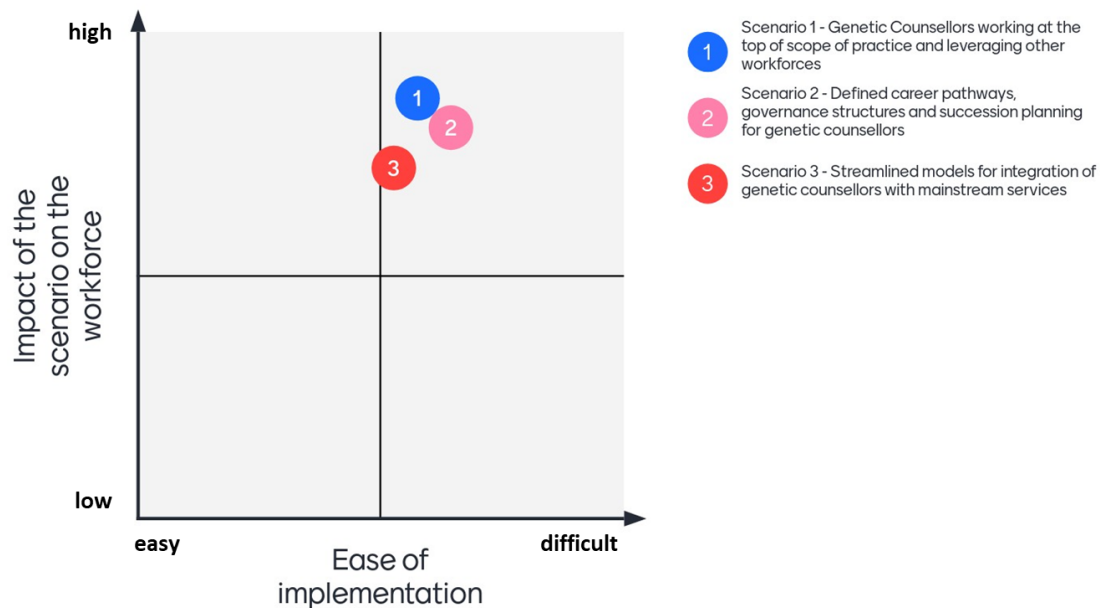
¹⁴ <https://onlinelibrary.wiley.com/doi/full/10.1007/s10897-015-9930-9>

Prioritising the Impact and implementation of scenarios

Workshop participants were asked to consider scenarios 1, 2 and 3 from the perspective of:

- Impact of the scenario on the workforce – with low impact indicating not much change from the current state and high impact indicating the scenario would move the workforce closer to the future vision.
- Ease of implementation – easy or difficult to implement.

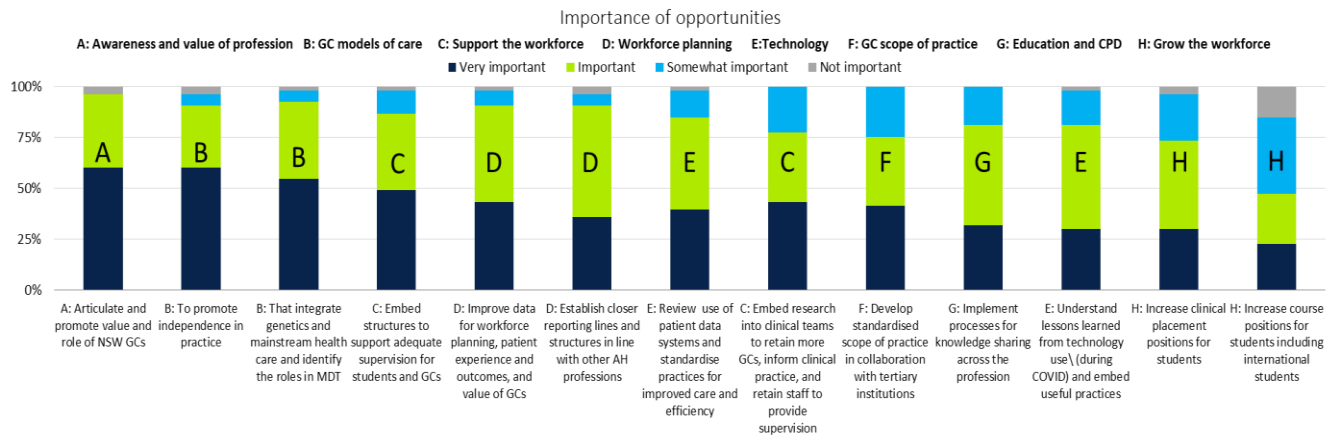
All three scenarios were considered likely to have a medium to high impact on the workforce and a moderate ease of implementation. Scenario 1 (working at top of scope) was identified as having the highest impact on the workforce and Scenario 2 (career pathways) was considered slightly more difficult to implement.



Survey findings

Survey respondents were presented with 13 workforce opportunities for consideration. Respondents were asked to rate how important each opportunity was in supporting the future workforce, as illustrated in Figure 14. The highest rated opportunities related to awareness and value of the profession and genetic counsellor models of care. All opportunities were rated as important, except for increased course positions for students including international students. Although 'grow the workforce' drivers were rated lower, most opportunities that were suggested included increasing the workforce, specifically relating to funding for genetic counsellor roles.

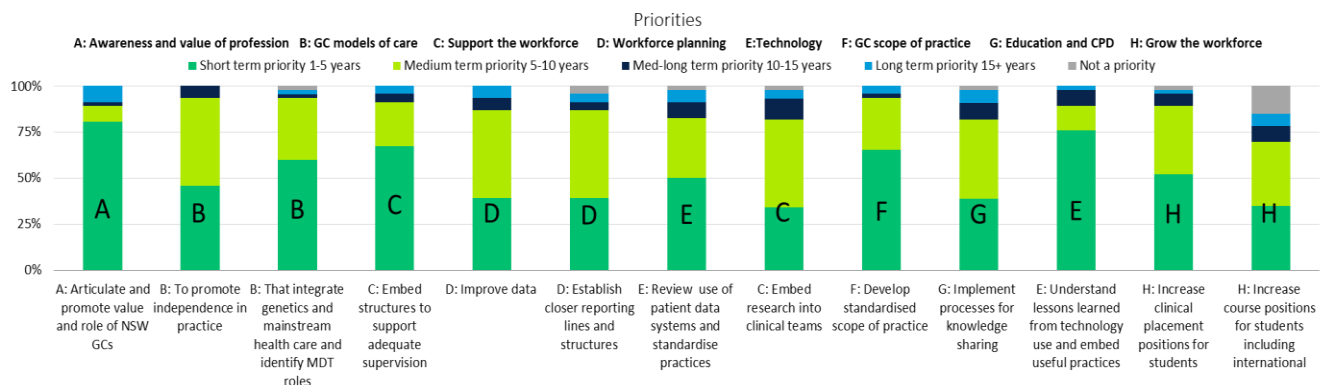
Figure 14: Importance of workforce opportunities



Prioritisation of opportunities

Opportunities were generally considered to be of short-term (1-5 years) and medium-term (5-10 years) priority. Articulating and promoting the value and role of NSW genetic counsellors and understanding lessons learned from technology use (during COVID-19) and embedding useful practices could be quick wins. Embedding structures to support adequate supervision and developing a standardised scope of practice were also seen as 1-5 years priorities. Other suggested priorities were defining specific genetic counselling outcomes, reporting and implementing a single electronic medical record, refer Figure 15.

Figure 15: Prioritisation of opportunities



Key actions for effective workforce change

These suggested key actions focus on translating the findings from this project into practical actions for future workforce modelling and planning of the genetic counsellor workforce in NSW Health. The suggested actions provide the practical next steps for which there is good evidence, widespread support, and clearly viable avenues for innovative workforce plans and implementation of opportunities.

1. Develop a plan to raise awareness of the workforce and build stronger relationships with key stakeholders.

There are opportunities to raise awareness about the role and value of the genetic counsellor workforce and build stronger relationships with key stakeholders including local senior management, Directors of Allied Health, the allied health workforce, and mainstream specialties.

Promoting the profession and the value of genetic counsellors among other health professionals and the broader population may support genetic counsellors in the mainstreaming of genomic services. It may also further assist genetic counsellors to work at top of scope and enhance opportunities for career progression and leadership positions.

Raising awareness of the profession will assist in promoting a shared understanding of the work undertaken by genetic counsellors, their value across the health system and establish future workforce needs. The Australian Society of Genetic Counsellors may be a useful partner to support this action.

2. Undertake a statewide workforce stocktake of genetic counsellors to better inform workforce planning and future workforce models.

Workforce planning is a foundational component in ensuring that NSW Health trains, recruits and retains a fit for purpose genetic counsellor workforce to effectively meet the needs of the population. Consistent and accurate full time equivalent and activity data will inform decision-making and allow strategic improvement at the service, LHD and state levels.

The current NSW Health genetic counsellor workforce data set identified some discrepancies in information as discussed at the workshops, and a validation of current data was considered beneficial. A statewide stocktake of genetic counsellors by LHD/SHNs will assist to verify current statewide data and accuracy.

Locally collected information on current activity, waiting lists and unmet need could also be used to highlight gaps in service provision and inform potential new workforce models for genetic counsellors such as centralised or hub and spoke models.

This information will serve as a valuable foundation for planning, delivering and evaluating genetic counsellor services in NSW in the future.

3. Engage the Genetic Counsellor Advisory Group to drive priority opportunities for implementation.

There is opportunity to agree and co-design new workforce priorities to support more effective demand management, mainstreaming of genomic services, patient access and experience, and staff satisfaction. Priorities identified include:

- A defined career pathway to support the workforce in achieving individual professional goals and in growing the capability and capacity of the workforce.
- A defined and documented role and scope of practice for genetic counsellors to support a clear and consistent understanding of the workforce and promote the value of the workforce - including exploring the opportunity for genetic counsellors working at top of scope of practice.
- Defined and documented roles for other supporting workforces, including administrative assistants and intake officers.
- Development of a strategy for integration of genetic counsellors into mainstream services considering different specialties needs, care settings and locations.

- Understand lessons learned from the implementation and use of technology (during COVID-19) and maximise this potential to support service delivery and equitable access

4. Explore potential data to demonstrate the value of the genetic counsellor workforce across the quadruple aim.

The NSW Health Genetic Counsellor Advisory Network, on behalf of genetic counsellors employed by NSW Health, should consider relevant data that would help establish a business case to expand the genetic counsellor workforce role and numbers. Key data will provide a platform for the workforce to demonstrate their value and advocate for strategic change. The establishment of any business case requires robust information to support informed decision making. Priority areas should include current activity and demand, patient outcomes and experience, clinician experience and system efficiency/effectiveness.

In exploring and considering relevant data measures for the genetic counsellor workforce, it is important to consider the following:

- the purpose of the data, for example, to demonstrate the value of genetic counsellors to other specialities, to support the case for growing the workforce (i.e. through administrative assistance, intake officers or genetic counsellors)
- data collections already in place, and how the data will be used internally or externally
- the method by which data will be collected, where the data will be reported and the frequency of data collection. As far as possible data should be easy and simple to collect
- the type of data required to identify meaningful trends in genetic counsellor services across the quadruple aim.

Attachment 1: Rapid literature review

Rapid literature review

December 2020

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INTRODUCTION

Background

Workforce Planning

The *NSW Health Professionals Workforce Plan 2012-2022* (NSW Ministry of Health, 2015) requires the NSW Ministry of Health to develop workforce modelling projections to 2030 for the Allied Health workforces (recommendation 7.8). The Health Professionals Workforce plan identifies a number of small but critical workforces that require attention in order to meet the needs of a changing health care service in NSW. Small but critical workforces are defined as: *'Workforces which contribute critical and essential elements of a comprehensive health service and are currently experiencing threats to meet systems needs now and into the future.'*

A Horizon Scanning and Scenario Generation Project will be undertaken by HealthConnect Consulting to identify the risks, issues and opportunities relating to the genetic counselling workforce including challenges and drivers that are expected to influence this profession in the future.

Genomic Strategy

Genomics is defined as the application of genome-based knowledge through the study of genes and other genetic information, their functions, and inter-relationships for the benefit of human health. Clinical genomics refers to the use of genomic information about an individual, a cancer or an infectious organism to inform clinical care (e.g., for prevention, diagnostic and/or therapeutic decision-making). The vision for NSW Health genomics is that by 2025 NSW Health will be recognised as a leader in the development and use of appropriate genomic technologies in health care and public health for the benefit of the NSW population (NSW Ministry of Health, 2017). Among the strategies to achieve this vision is workforce planning and training for genomics. To address the need for national harmonisation, the Commonwealth Department of Health has published the *National Health Genomics Policy Framework 2018-2021* (Australian Government Department of Health, 2017). Building a skilled workforce that is literate in genomics is a strategic priority in the Framework: *Upskilling the workforce through increasing capacity and capability in genomics and bioinformatics is necessary to effectively and efficiently support improved health outcomes for the individual and population.*

Aim

The rapid literature review (Review) will help inform the Horizon Scanning and Scenario Generation. The objectives of the Review are to develop a picture of the genetic counsellor workforce in NSW to understand the current service needs and future workforce requirements. The review provides an update on the key review questions included in the Evidence Check undertaken by the Sax Institute (Barlow-Stewart et al., 2017) and the Genetic Counselling Workforce Final report (Kurti et al., 2017). In particular, the Review seeks to identify: 1) current workforce profile, education needs and scope of practice; 2) best practice models; and, 3) workforce issues/challenges and potential future scope of practice.

METHOD

The Review followed the general process as outlined in the Virginia Commonwealth University (VCU) Research Guides Rapid Review Protocol¹⁵ and drew from the Cochrane Handbook for Systematic Reviews of Interventions.¹⁶ Given the nature of the questions and the broad type of information sourced (mostly

¹⁵ <https://guides.library.vcu.edu/rapidreview>

¹⁶ <https://training.cochrane.org/handbook/current>

commentary, policies, surveys), evidence quality grading was not used, however the scope of information, author and source provide a guide to the relevance and quality of reporting.

Search Strategy

Inclusion and exclusion criteria

Given the two recent reviews by the Sax Institute (Barlow-Stewart et al., 2017) and Urbis (Kurti et al., 2017), peer reviewed literature and grey literature (i.e. reports, guidelines and policies) were searched from 2016-present (i.e. last 5 years) and included primary documents from Australia, Canada, USA, United Kingdom and New Zealand. Key words, search terms and alternate terms* included:

<i>Workforce</i>	<i>Intervention/program types</i>
<ul style="list-style-type: none"> - Genetic counselling/counsellor(s) - Genomic counselling/counsellor(s) - Genetic service(s) 	<ul style="list-style-type: none"> • Prediction • Diagnosis • Prognosis • Screening • Interpretation • Education • Counselling • Support • health promotion • intervention • treatment • best practice • emerging models • technology assisted services • precision medicine • gene therapy
<i>Population/locations</i> <ul style="list-style-type: none"> - All age groups - All locations i.e. rural, regional, metro 	
<i>Settings</i> <ul style="list-style-type: none"> - hospital clinics - community health centres/services - specialty health related services – cancer clinics/oncology, prenatal clinics, paediatrics, obstetrics and maternal health, gynaecology, genetic heart disease clinics/cardiology, neurological clinics - specialised genetic services 	

Primary document search

A document search was performed on 3 December 2020 by the NSW Ministry of Health's Library with the following databases and search terms:

Search Embase, Emcare, Medline, PreMed, Psyc, Cochrane

(Genetic counseling/ or genetic counsel* or Genomic counsel*.mp. or Genetic services/ or genetic services.mp.) AND (Workforce/ or Health Workforce/) AND (Australia or New Zealand or Canada or UK or England or United States); 2016- ; Eng.

Search Ac S Comp, ERIC, Edn S., Health Bus E

AB (genomic counsel? or genetic counsel? or genetic service?) OR TI (genomic counsel? or genetic counsel? or genetic service?) AND (health workforce or health workers or allied health) AND (australia or new zealand or england or uk or canada); 2016-

Search Nurs&AllHealth

Mainsubject (Genetic counseling or Genetic services) AND (health care workforce or health workforce) AND ab (australia or new zealand or canada or united states or uk or england)

Search Emerald

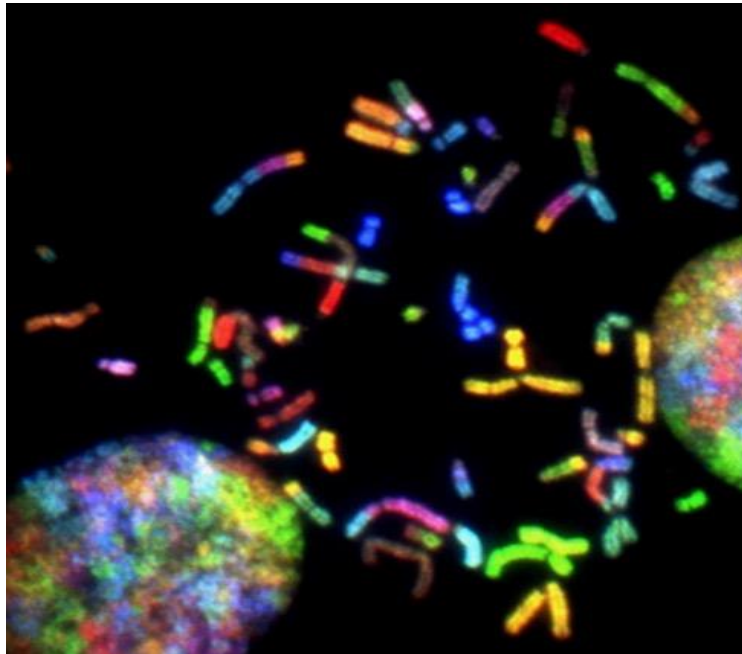
(Genetic counseling or Genetic services) AND (health care workforce or health workforce)

The search revealed 45 citations whose abstracts were reviewed manually. 12 citations were excluded as they were not relevant to the review questions and mostly focussed on the broad topic of genomics and other healthcare professions. 33 were selected for full length manuscript review, of which 27 were used in the Review.

Additional documents search

An additional search for documents was conducted on key sites identified by the Ministry of Health (and others) and referenced in documents, including for example: Human Genetics Society of Australasia, Australian Society of Genetic Counsellors and Australian Genomics Health Alliance. This search yielded 30 additional documents (including relevant NSW policy documents and plans).

Trends and commentary were searched for on recent social media (e.g., Facebook) and University sites; this yielded further searches on other sites and relevant information is reported on where applicable to the review questions.



REVIEW QUESTIONS

a) What are the current roles, scope of practice and best practice of genetic counsellors (including those specifically in NSW Health)?

b) What are the educational needs of this workforce?

“A genetic counsellor is like air conditioning. When you do not have it, you do not realize you are missing it, but when you have it, you cannot live without it!” (Abacan et al., 2019).

Genetic Counsellors¹⁷

The *NSW Health Genomics Strategy* defines genetic counsellors as “Healthcare professionals who have undergone speciality training to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions” (NSW Ministry of Health, 2017, p. 44).

Genetic counsellors are allied health professionals who have specialist knowledge in human genetics, counselling and health communication skills. They provide information to individuals and families about genetic conditions, which may involve learning about conditions that are inherited or who in the family may be at risk of developing a particular condition. Genetic counsellors also provide emotional and practical support to help people adjust to living with, or being at risk for, a genetic condition. There are a wide range of reasons to see a genetic counsellor, but some typical reasons include:

- couples planning a family who want information about the chance of having a child with a genetic condition
- people who have a personal or family history of young onset cancer, particularly breast, ovarian or bowel cancer
- people who have a family history of a genetic condition or are concerned that they have symptoms of a genetic condition.

Genetic counsellors work in a range of settings including hospitals and community health centres, medical specialist clinics, obstetric ultrasound practices, research institutions, genetics laboratories and policy and project roles with government. They work as part of a team, usually with medical specialists such as clinical geneticists, oncologists, obstetricians, neurologists and cardiologists. There are genetic conditions in practically every medical specialty for which genetic counselling may be sought. With advances in genetic testing technologies genetic counsellors are being called upon by other specialities to work with families whose healthcare may benefit from the genetic information these technologies can bring.

Public sector genetic services are governed by Local Health Districts (LHDs) and Speciality Health Networks (SHNs). Genetic services, including genetic counselling, are offered through clinics located within tertiary hospitals, or as outreach units (e.g., community health centres) in regional and rural areas linked with a primary unit located in a city hospital (Centre for Genetics Education, 2016 cited in Kurti et al., 2017, p. 3). Two other main providers of genetic counselling within the NSW public health sector include: clinics that offer speciality health related services, such as cancer clinics, prenatal clinics, genetic heart disease clinics and neurological clinics; and specialised genetic services that involve services that specialise in the management for people affected by particular genetic conditions and risk assessment for concerned family members (Kurti et al., 2017, p. 4).

¹⁷ Information in this section is from <https://ahpa.com.au/allied-health-professions/genetic-counselling/> and <https://ahpa.com.au/allied-health-professions/genetic-counselling/>

Roles

Genetic counselling is a rapidly evolving, dynamic profession and the breadth and nature of professional practice within the profession of genetic counselling continues to expand (Human Genetics Society of Australasia, December 2019). As noted in the review by Urbis (Kurti et al., 2017), international literature suggests that different medical and non-medical professionals are commonly involved in the provision of genetic counselling, and key elements of ‘the act of providing genetic counselling’ appear to be widely used in various health settings. Their review indicated that there are two types of professionals involved in genetic counselling:

- professionals involved in genetics (e.g., genetic counsellors, clinical geneticists)
- other healthcare professionals using genetics in routine care, such as general practitioners, specialists (e.g., oncologists, cardiologists, obstetricians, neurologists), nurses, psychologists, and social workers.

The Urbis review highlighted considerable variation in role scope of genetic counsellors and outlined some of the contextual influences enabled by one or all of the health system characteristics (Kurti et al., 2017):

- Non-centralised provision of public sector genetic services: there is less variation in the services provided by genetic counsellors, and greater consistency in clinical governance and supervisory practices, in states and territories with centralised genetic services (e.g., Victoria and Queensland).. Counsellors in these jurisdictions are also required to adhere to consistent protocols and procedures, including scope of practice and governance arrangements.
- Lack of formal clinical oversight of public sector genetic services: it is possible to promote consistency in role scope and subsequent service delivery, at least in the public sector, through the provision of mandated clinical guidelines or, some form of centralised clinical oversight.
- Status as a non-registered health profession: this has partly been addressed through self-regulation (see below).

Kurti et al. also reported that the role scope for genetic counsellors can differ substantially depending on medical specialisation (i.e., common sites for service delivery, types of services provided and typical team structures).

While the majority of genetic counsellors are engaged in clinical roles in public hospitals, many more are entering private practice and they are also engaged in management, education, research and policy roles (Human Genetics Society of Australasia, 2020). Genetic counsellors provide the most up to date information and support to individuals and families who have a condition that may have a genetic basis. Where there is a genetic condition in a family, the genetic counselling team may (Centre for Genetics Education, 2020):

- estimate the chance that other relatives, or children, will be affected by the condition
- discuss the impact and possible effects on the individual and their family for some conditions, develop management strategies
- refer to appropriate community resources and support groups
- discuss and arrange appropriate genetic or genomic testing where available
- discuss, if relevant, prenatal testing and other reproductive options.

A genetic counsellor can provide both verbal and written information about the condition and its impact to assist people in dealing with some of the issues that may arise from the diagnosis of a genetic condition. Genetic counselling is not primarily counselling in the psychological sense, although the genetic counsellor will address emotional and psychological issues raised during a consultation, and may be able to assist individuals in adapting to new information (Centre for Genetics Education, 2020). However it has been noted that a key difference between genetic counselling as practiced by genetic counsellors and genetic counselling as practiced

by other health professionals is the focus on psychosocial issues and the therapeutic relationship that genetic counsellors develop with clients and families with or at risk of genetic conditions (McEwen & Jacobs, 2020b).

Scope of practice

The Human Genetics Society of Australasia's (HGSA) policy (Human Genetics Society of Australasia, December 2019) provides the most recent scope of practice:

- Obtain and evaluate individual, family, and medical histories to determine genetic risk for genetic/medical conditions and diseases in a patient, his/her offspring, and other family members
- Discuss the features, natural history, means of diagnosis, genetic and environmental factors, and management of risk for genetic/medical conditions and diseases
- Identify, coordinate, and facilitate informed consent of appropriate genetic/genomic tests and other diagnostic studies as appropriate for the genetic assessment
- Integrate clinical and psychosocial implications of genetic/genomic test results and other diagnostic studies with personal and family medical history to assess and communicate risk factors for genetic/medical conditions and diseases
- Explain the clinical and psychosocial implications of genetic/genomic tests and other diagnostic studies and their results
- Provide client-centred counselling and anticipatory guidance; evaluate the client's or family's responses to the information discussed; and assess and support adjustment to the information provided
- Identify and utilise community resources that provide medical, educational, financial, and psychosocial support and advocacy; and provide written documentation of medical, genetic, and counselling information for families and health care professionals
- Engage in regular supervision that encourages self-reflection and continued development of personal practice
- Continually develop critical skills in logical philosophical reasoning through engagement in Continuing Professional Development in order to rationally resolve the individual cases of ethical conflict that arise in the work setting
- In addition to those working in clinical roles, genetic counsellors engaged in roles including management, administration, education, research, laboratory, advisory, regulatory and policy development roles should strive to achieve and maintain best practice.

Genetic counselling outcomes

Redlinger-Grosse et al. used an online, modified Delphi method to prioritise genetic counselling outcomes from the viewpoint of individuals from four stakeholder groups – clinical genetic counsellors, outcome researchers, genetic counselling training directors, and genetic counselling consumers/advocates (Redlinger-Grosse, MacFarlane, Cragun, & Zierhut, 2020). Process outcomes such as patient's informational needs and delivery of information in a collaborative, compassionate, and patient-centred manner were among those with the highest relative importance. Patient health outcomes were absent from the most highly rated outcomes. However, the authors suggested that if genetic counsellors become more embedded in various healthcare specialties, they could take on longer-term follow-up roles such as coordination of care that directly relates to medical management of patients, thereby having a more direct impact on patient health. Clinical genetic counsellors had the highest degree of similarity with consumers, suggesting they are more in touch with what is important to patients than are the researchers or educators.



Education

Genetic counsellors have specialised education in genetics and counselling. In order to practice in Australia, a genetic counsellor must complete the following:

- A clinical Masters of Genetic Counselling degree approved by the Board of Censors for Genetic Counselling (under the auspices of the HGSA)
- A minimum of 2 years on the job training to become a Certified Genetic Counsellor.

There are two HGSA Accredited Courses in Australia.

- Master of Genetic Counselling, University of Technology Sydney (UTS) - Provisional accreditation of this course was granted in December 2018. UTS also offers: Master of Genetic Counselling (Research) and a Doctor of Philosophy (Genetic Counselling).
- Master of Genetic Counselling, University of Melbourne (UniMelb)- a professionally accredited coursework degree, completed full time over two years.

The Melbourne Medical School's existing relationship with associated institutes, such as the Murdoch Children's Research Institute and Victorian Clinical Genetic Services (VCGS), provides close access to world-class clinical research and laboratory science facilities. The UTS course recognised the need for changes in diversity of people entering the profession and in the provision of culturally safe genetic counselling. The UTS program actively supports students to study from their home areas by using a combination of asynchronous interactive online learning and synchronous weekly, timetabled 'live and online' classes, supported with an on campus block each semester. (McEwen & Jacobs, 2020a). This allows students to remain within their own communities and support networks and continuing to meet pre-existing family and community responsibilities.

A review of the Masters of Genetic Counseling (MGC) at the UniMelb was undertaken in 2016/2017. The curriculum was updated to reflect emerging technologies and practice, and in accordance with training guidelines outlined by the HGSA. The delivery of course content was reconsidered in favour of incorporating a 'blended learning' approach (i.e., online and face-to-face learning activities and assessments). In addition to the revised MGC program, the Masters of Genomics and Health (MGH) was also launched. This qualification was developed in recognition of the need to prepare a workforce that is knowledgeable and skilled in the practical, ethical and socially responsible implementation of genomics. In 2018 there were 20 students enrolled in the MGC and 15 enrolled in the MGH at the UniMelb (Reid & Charles, 2019).

*Certification and regulation*¹⁸

- Following successful completion of the Masters of Genetic Counselling degree, individuals can seek employment as a genetic counsellor and apply for Board Eligibility to certify with the HGSA.

¹⁸ <https://www.hgsa.org.au/resources/genetic-counselling/genetic-counsellor-training-certification-and-regulation-in-australia-and-new-zealand>

- Board eligible genetic counsellors are granted the title 'Member of the HGSA'.
- Once practicing, board eligible genetic counsellors can complete the training required for HGSA Board Certification which assesses the knowledge, skills and competency of the individual in a clinical role over two years.
- Successful completion of this training enables the individual to use the title 'Genetic Counsellor, Fellow HGSA'.
- Once certified, genetic counsellors are expected to participate in Continuing Professional Development (CPD) and ongoing practice.
- Genetic counsellors who meet CPD and practice requirements through the HGSA are listed in an online Register.

The HGSA has published competency standards required for genetic counselling practice and which must be demonstrated to attain certification.¹⁹ The five standards cover competencies in communication skills, reflective practice, counselling and interview skills, critical thinking skills, case management skills and professional and ethical practice.

Historically, HGSA Board Certification was developed and solely based on assessing competency for genetic counsellors practicing clinically. As the profession has developed and expanded into other roles, it has become apparent that the process of certification is not inclusive of current and emerging roles (including management, administration, education, academia, industry, research, advisory and policy roles). There is a clear intent by the HGSA to develop a more inclusive and expansive framework over time (Hoskins et al., 2020).

A key action in the *Implementation Plan: National Health Genomics Policy Framework 2018–2021* (Department of Health, 2018) is to consider opportunities to identify and promote best practice in genetic counselling and recognise genetic counsellors as a self-regulating health profession underpinned by the AHMAC-endorsed code of conduct for unregistered health practitioners.

The HGSA and the Australasian Society of Genetic Counsellors (ASGC) identified regulation of the genetic counselling profession as a priority. In Australia, the National Alliance of Self-Regulating Health Professions (NASRHP) is the national peak body that provides regulatory standards for allied health professions. The ASGC is also a member of Allied Health Professions Australia (AHPA), the peak national organisation for allied health professions, representing, advocating, and providing strategic leadership for allied health professions in Australia (See Appendix 1 for more details on these professional organisations and regulation).

In 2020, the HGSA Board of Censors for Genetic Counselling was granted full NASRHP membership for the regulation of genetic counsellors. Hoskins et al. detail the process of formalising self-regulation (Hoskins et al., 2020). The HGSA Implementation Committee for Genetic Counsellor Regulation is supporting the Board and genetic counsellors in the transition to formal regulation (to March 2023). The Implementation Committee is also using NASRHP membership as a foundation to pursue:

- Statutory/legislative endorsement of regulation by Commonwealth, State, and Territory governments
- National title/career structures and title protection for genetic counsellors
- Models of funding for genetic counselling (including ABF, Medicare, private insurance).

Professional regulation has a benefit of enhancing professional standing and autonomy, enabling genetic counsellors to help shape the future of genetic health care in Australia (McEwen & Jacobs, 2020a).

¹⁹ See full document at <https://www.hgsa.org.au/documents/item/10550>

What are the emerging challenges for the genetic counselling workforce?

Genomics

Genomics play a role in 9 of the 10 leading causes of death, including heart diseases, stroke, diabetes and Alzheimer's disease. The application of genomic knowledge is transforming the way healthcare is being and will be delivered and genomic medicine has the capacity to enable precision or personalised medicine for individuals (NSW Ministry of Health, 2017). Successful implementation of genomic technology relies on whole-of-system change. Genomic medicine promises better patient outcomes and a more efficient health system through rapid diagnosis, early intervention, prevention and targeted therapy.

In the next five years, genomic data from an estimated 60 million patients globally is expected to be generated from health care. The volume and complexity of that data – and how it is accessed, shared and applied – are enormous. So too are the associated issues around genomic medicine such as data storage, ethics and privacy, nationally consistent practices, patient access, economic impact and workforce capability.²⁰

As outlined in the *NSW Genomic Strategy*, the speed and trajectory of the technology advances in genomics presents unique challenges. Large-scale sequencing is now possible, cost of testing is lower and with the availability of high-speed computing to support sophisticated analysis, it is feasible for genomics to become a part of routine healthcare (NSW Ministry of Health, 2017, p. 4). This is compounded by rising consumer interest in, and demand for, genomic services, as well as the increasing availability of tests being offered by providers. These tests may be for specialised disease specific purposes or generic risk assessment, wellness or ancestry analysis (NSW Ministry of Health, 2017, p. 7).



Workforce

The rise of genomic medicine presents a major workforce development challenge for healthcare professions and organisations, including NSW Health. Making genetics and genomics an integral part of mainstream clinical practice will change this profoundly. (NSW Ministry of Health, 2017, p. 36). The *NSW Health Genomic Strategy Implementation Plan 2018-2020* prioritises identifying and describing the genomics workforce roles that are critical to current and anticipated future workforce demands and improving genomics education (NSW Ministry of Health, 2018).

The Commonwealth is funding research into mapping workforce needs as a first step in understanding gaps and opportunities. The delivery of safe, effective, cost-effective and ethically informed services is reliant on cross-disciplinary collaboration to shape the role of genomics in health care. There is a growing need not only for genomics specialists but also for a range of health professionals in translating findings from a research environment into a clinical context (Department of Health, 2018). Action 10 of the *Implementation Plan for the National Health Genomics Policy Framework* is: *Consider opportunities to identify and promote best practice in*

²⁰ <https://www.australiangenomics.org.au/about-us/australian-genomics/>

genetic counselling and recognise genetic counsellors as a self-regulating health profession underpinned by the AHMAC endorsed code of conduct for unregistered health practitioners.

Medical specialities such as cardiologists, oncologists and obstetricians are having an increasing role in the provision of clinical genomics services, including providing genetic counselling. Currently, there are limited workforce training and education opportunities to ensure the broader health workforce has the genomic literacy and capability to deliver quality and safe clinical genomic services. For genomic knowledge to be integrated into the health system, it is critical that the broader health workforce develop an understanding of the application of genomics to health care (Australian Health Ministers' Advisory Council, 2017).

Internationally, genetic testing is shifting toward gene panels and genomic testing, including whole exome sequencing (WES) and whole genome sequencing (WGS)²¹ to improve diagnostic yield and cost-effectiveness (Dwarte et al., 2019).

The Urbis review outlined emerging challenges for the genetic counselling workforce based on the literature and stakeholder input, which are summarised below.

- The transition from genetic counsellor to “genomic counsellor”:
 - Increased role in preventative health
 - New service delivery models (e.g., technology assisted distance genetic counselling)
 - Increased number of conditions included in testing resulting in potentially increased workload and/or specialisation
 - Increased number of ‘positive’ and uncertain results, and overall increased number of disclosed results (Dwarte et al., 2019; Thomassen Hammerstad et al., 2020)
 - Increased time spent with clinicians (see also (Dwarte et al., 2019).
- Matching supply and demand for genetic counselling services.
- Health profession registration and education pathways.

Most of these challenges relate to the growing field of genomic testing, increased demand for genetic services and the related workforce issues. Appendix 2 also provides a summary of challenges reported in the Sax review (Barlow-Stewart et al., 2017), many of which are still current and overlap with those identified by Kurti et al. (2017). Some of these challenges have already been or are being addressed such as health profession registration.

Laurino et al. reported on the Professional Society of Genetic Counselors in Asia (PSGCA) which was formally launched during the Genetic Counseling Pre-Conference Workshop held at the 11th Asia-Pacific Conference on Human Genetics in Vietnam (Laurino et al., 2018). Genetic counsellors currently practising in the region cited their main challenges as:

- Limited availability of professional development and research opportunities
- Lack of training program accreditation, professional licensure, and ongoing quest for autonomy
- Unclear definition of genetic counsellors’ professional role and scope of practice
- Incomplete integration of genetic counselling services into the healthcare system including specialty areas (e.g., cardiology, neurology, etc.)
- Lack of published practice guidelines specific for genetic counsellors practicing in the Asia Pacific and standards of practice to benchmark genetic counselling competencies

²¹ Exome is part of the genome formed by exons, the sequences which, when transcribed remain within the mature RNA after introns are removed by RNA splicing. WES is a laboratory technique for sequencing all the known protein-coding regions of DNA in an organism’s genome (known as the exome). WGS is a laboratory process to determine the complete DNA sequence of an organism’s genome.

- Provision of culturally relevant genetic counselling to diverse populations and triaging of numerous genetic diseases with insufficient genetic counsellor and medical geneticists in the region.

Kurti et al. (2017) suggest that workforce planning and service delivery re-design will assist in ensuring that these challenges are overcome, and genetic counsellors can continue to deliver high quality services to NSW patients. It was suggested that elements of planning and re-design could focus on the role of genetic counsellors and activity of genetic counselling.

Education and Workforce Development

As genomic medicine integrates into mainstream healthcare, issues around workforce capability and education arise. Genetic counsellors are part of the Clinical Genetics Network at the NSW Agency for Clinical Innovation (ACI) which provides expert advice on genetic services and assists in the development and implementation of new or improved models of care to improve health outcomes for people living in NSW. The role of the network includes the review and updating of state-wide policies and guidelines and development of patient consent forms and consumer information.

The Australian Genomics Health Alliance was launched in 2016 to address many of the workforce capability and education challenges and to build the evidence to inform the integration of genomic medicine into mainstream healthcare. A diverse program of research is being undertaken to address evidence gaps, including research into workforce development and education. The Genomics Workforce and Education program of the Australian Genomics Health Alliance²² is investigating issues such as: are education providers, including universities, able to meet the demands for this new knowledge and skills; and, are they providing relevant and accessible training in genomic medicine? Australian Genomics formed Genomics Education Network of Australasia (GENA) in mid-2018 to foster a community of evidence-based practice and to share experiences, tools and exemplars of health professional genomics education and evaluation.

As noted above, genomics education for the health workforce is a priority, since genomic information is increasingly used in routine healthcare (Martindale, Crerar, Davis, McInerney-Leo, & McEwen, 2020). In order to understand the current landscape of Australian genomics education, McLaren et al. mapped education activities in genomics available in 2016 and interviewed education providers through 2017 (McClaren et al., 2018). Fifty-nine education activities or resources were identified with 81 per cent being national or based in New South Wales or Victoria. Programs were aimed at health professionals, genetic professionals, medical scientists and/or clinical bioinformaticians. There were seven genomic education programs identified targeted to genetic counsellors, clinical geneticists and medical specialists with training in genetics. Genomic education programs appeared to have been developed in response to local health care system needs and introduction of new technology, rather than as part of a strategic approach to genetic or genomic education. Many activities were developed by people without an education qualification and few were based on formal needs assessments or evaluated to determine quality and/or effectiveness.

In other countries, such as Canada, the National Society of Genetic Counselors' (NSGC) is looking to advance the genetic counselling profession's achievement of the NSGC's strategic objectives through research (Senter et al., 2020). Their research agenda outlines high-priority research questions organised into four domains. Some examples of priority questions are noted below:

<p>Genetic counselling clients</p> <ul style="list-style-type: none"> ○ What clinical, psychological, behavioural, and/or social factors predict need for and/or benefit from genetic counselling? 	<p>Access to genetic counselling services</p> <ul style="list-style-type: none"> ○ Which policies reduce barriers/promote access to genetic counselling services and how? ○ What are the common pathways and referral patterns to genetic counselling? ○ How does the changing landscape of access to genetic testing impact the entry points to genetic counselling services?
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²² <https://www.australiangenomics.org.au/our-research/workforce-and-education/#1543233471978-5579adfe-ce08>

Genetic counselling process and outcomes

- What are the common and specific elements of genetic counselling models, and what are the critical/most efficacious components of these models?
- How do we enable genetic counsellors to practice more effectively and at the top of their scope (e.g., using electronic medical records, genetic counselling assistants/extenders, video information, questionnaire, chatbots)?

Value of genetic counselling services

- How do we define value in genetic counselling?
- What are the relevant variables and components of the value equation? [e.g., Value = Quality/Cost? or Value = (Safety + Efficacy + Patient Experience)/(Costs incurred – Costs avoided), other?]

Increasing capacity and capability in genomics is necessary to support the improved health outcomes promised by genomic medicine. The issue of workforce skilling recognises that many types of healthcare professionals will need varying degrees of genomic literacy as the implementation of genomic medicine proceeds. As noted by the Global Genomics Medicine Collaborative²³, there is also an awareness that there is great potential to share training and education material to avoid duplication of effort. With this in mind, a number of entities have made their training material freely available for others to use and adapt. Within the Catalogue of Global Genomic Medicine Implementation Initiatives²⁴, over half of the initiatives (34/61) gave some acknowledgement to workforce issues.

The implementation initiatives show there is a need to develop, deliver and maintain genomic education, training and skills for a range of different professional groups. These programs need to be created and delivered in culturally responsive ways and should also have certification and/or accreditation to provide consumers with confidence in the health workforce. As the role of genomics will continue to change, most health systems need to develop workforce plans and strategies (e.g., audit and assessment of roles and skills) including new service delivery models.

An interview study of individuals with advanced training in genetic counselling (US based) indicated preference for a model of advanced training that illustrates multiple paths to diverse skill sets and possible roles. Recommendations for optimal use of the model included development of an online career resource that is approachable, interactive, sustainable, responsive, and inspiring. Establishing a genetic counsellor career lattice with additional resources (e.g., examples of institutional career ladders, case histories of career ladder development, and international examples) would serve as a springboard for institutions to develop institution-specific career ladders, for individuals to explore career options, and for the field to consider career enrichment will support further development of the profession (Baty, Davis, Erby, Hippman, & Trepanier, 2020).

Supply and Demand

Almost all stakeholders involved in the Urbis review reported that demand for genetic testing was increasing and, as a result, the need for genetic counsellors, or at least clinicians with clinical genetics and counselling skills, was also increasing. Ongoing advances in genetic technologies are resulting in vast amounts of information being available to clinicians, patients and their families, contributing to the rapid expansion of the profession (Barlow-Stewart et al., 2017; Human Genetics Society of Australasia, 2020). There was also a consensus that, at least within NSW Health, there is not currently an adequate number of clinical genetics staff (including counsellors) to meet the increasing demand (Kurti et al., 2017).

Based on US and Canadian employment data, employment of genetic counsellors is projected to grow much higher than the average for all occupations (Careercast, 2018). The increasing availability of and demand for genomic information significantly increases the likelihood of harm to the public from unqualified healthcare providers offering services in a highly complex and rapidly changing field (Human Genetics Society of Australasia, 2020). Based on ASGC membership data, in 2019 there were only an estimated 202 genetic

²³ <https://www.genomicspolicy.org/workforce-skilling?rq=genetic%20counseling>

²⁴ <https://www.genomicspolicy.org/catalogue-introduction>

counsellors working in fully clinical roles in Australia and New Zealand, 85 of whom were fully certified by the HGSA. The National Framework (2017) indicates there are 280 accredited genetic counsellors and trainees (as members of the Australasian Society of Genetic Counsellors, special interest group of HGSA). Even though numbers have increased there is increasing evidence that the number of genetics healthcare professionals internationally is insufficient to meet the growing demand for genomics (Nisselle et al., 2019).

‘Genetic counsellor’ was reported to be best job in healthcare in 2018²⁵ and ranked 5th in 2019²⁶, owing its popularity and demand to exponential growth in technology. In the US, the genetic counselling profession has grown by over 100% in the last ten years and with continued expected growth; in Canada the growth has been 65% (Hooker et al., 2020). Based on NSW Health modelling and projections, the growth for Genetic Counsellors from 2019-2035 is 5.4%.

As part of a Wisconsin study, workforce supply and demand models from Dobson and DaVanzo²⁷ in 2016 provided an assumption that there should be one full-time equivalent (FTE) certified genetic counsellor for every 75,000 individuals in the population (Dawson et al., 2020; Hoskovec et al., 2018). As genetic counselling becomes increasingly crucial to patient care across specialties, 55 per cent of Wisconsin genetic counsellors reported being stressed or highly stressed, and many considered or already have changed to non-clinical roles. Capacity to increase patient volumes may be realised by having genetic counsellors work to their highest scope of practice, which may be achieved by increasing support personnel to assist with case management (see later section on assistants).

Based on a survey of recent Canadian genetic counselling graduates and employers of genetic counsellors, Costa et al. found the specialties in highest demand and the most common areas of practice for recent graduates included adult general genetics, prenatal genetics, and cancer genetics (Costa, Gillies, Oh, & Scott, 2020). Their findings suggest that there is a growth of employment opportunities in Canada and more employer-reported need for clinical genetic counsellors however, there is a lack of funding to support this expansion.

Nisselle et al. conducted a census of Australian genetic counsellors and clinical geneticists to ascertain education, practice, capability and readiness to provide genomic medicine (Nisselle et al., 2019). The potential genetic counselling workforce in 2017 was estimated to be 480 currently working in genetics. A summary of data pertaining to genetic counsellors is provided below:

96.3% female	32.6% performed education as part of their job
7.7% aged over 55 years	64.9% were employed in public hospitals or healthcare provider organisations
33.4% with a genetic counselling qualification were certified genetic counsellors	22.5% had more than one job, totalling median 1.0 FTE
7.6% not employed in a job related to genetics	65.9% of clinical genetic counsellors saw general genetics patients plus specialty patients 14.9% solely cancer patients 7.3% solely prenatal patients
65.9% employed in a clinical role	91.1% “satisfied” or “very satisfied” with their job
43.2% job had a research component	93.3% planned to stay (or commence) working in the field until retirement, either in clinical, education or administrative roles
4.2% laboratory activities formed a part of their daily activities	14.1% planned to retire within 10 years

Other Emerging Issues

Insurance

Within Australia health insurance is community rated, meaning genetic results cannot be used to exclude people or charge them different rates for that policy. However, in Australia and New Zealand, insurance

²⁵ <https://www.careercast.com/jobs-rated/2018-jobs-rated-report>

²⁶ <https://www.careercast.com/jobs-rated/2019-jobs-rated-report>

²⁷ https://www.abgc.net/abgc/media/documents/dobson-davanzo-report-to-nsgc_final-report-9-6-16.pdf

companies can use genetic test results as a basis for refusal of cover or increased premiums for mutually-rated insurance products, such as life insurance, income protection and disability insurance. Genetics professionals regularly discuss insurance implications with clients and report the issue as a clinical challenge (Tiller et al., 2018). In a survey of genetic counsellors and clinical geneticists in Australia and New Zealand, Tiller et al. found there was considerable variability in training and clinical policies, especially around the communication of insurance implications. Almost half of participants reported receiving no training on the insurance implications of genetic testing, and almost 40 per cent were unsure whether they could adequately advise clients. Widespread concerns regarding regulation of this area were reported, with fewer than 10 per cent of Australian participants considering current Australian regulations as adequate to protect clients from genetic discrimination.

What is the future scope of practice for the genetic counselling workforce?

While there are numerous challenges facing the field of genomics, they present as opportunities for growth and development for the genetic counsellor workforce.

“There are few fields that are as rapidly evolving as genetics and the explosion of technology is opening up endless possibilities for genetic counsellors... while there will always be a need for clinical practice, education for non-genetic clinicians like GPs, community paediatricians and community groups is a burgeoning huge area as well. With the fast-paced growth of technology there is a constant and ever-growing demand from non-genetics areas of medicine to understand this and genetic counsellors are perfectly positioned to be the translators.”²⁸

Genetics is increasingly being recognised as an important component of many aspects of healthcare, and the contribution of genetic counsellors’ specialised skill-set contributes to the safe implementation of genetic technologies to improve patient outcomes (Human Genetics Society of Australasia, 2020). The speed and cost-effectiveness of next-generation sequencing (NGS) and subsequent increased feasibility of offering genetic/genomic testing in the clinical setting have led to a paradigm shift in genetic counselling practice (Dwarte et al., 2019). Genetic counsellors, especially specialist counsellors, are well-placed to play a role in ‘managing the influx of genetic information both in clinical and laboratory settings’, including communication with and education of non-genetic specialists (Kurti et al., 2017).

Urbis report suggests there are opportunities to expand the role and expand the activity of genetic counselling. Tan et al. demonstrated that the inclusion of a genetic counsellor in a Singapore Cancer Genetics service increased clinic capacity by 350% (Tan et al., 2016). Richardson et al. found that streamlined oncology clinic-based genetic testing using a multi-gene panel approach and post-test counselling with a genetic counsellor reduced wait times for genetic testing and was acceptable for patients and health care providers (Richardson et al., 2020). Similar models using Australian oncologists to provide BRCA1 and BRCA2 genetic testing have already been used in Australia (Kentwell et al. 2017, cited in Richardson et al., 2020).

However, service expansion is limited both by the number of genetic counsellors and by the number of clinical geneticists who can provide supervision. Kurti et al. (2017) indicated that if workforce shortages persist, alternative models may need to be developed, including models which widen the scope for genetic counsellors to work in additional settings, potentially with less direct oversight by clinical geneticists.

Core skills required now and into the future

Although the application of genomic knowledge is transforming the way healthcare is being delivered and the types of roles for genetic counsellors increasing, the literature indicates that the core skills of genetic counsellors are highly valued now and will remain critical into the future. Core genetic counselling skills are seen to have consistently supported the adaptation to advances in genetic technologies and practice demands (Dwarte et al., 2019, p. 384).

Benjamin et al. describe empirical research undertaken in 2016 that provides an insight into UK genetic counsellors’ opinions about their current role and future opportunities and challenges (Benjamin et al., 2020).

²⁸ <https://www.uts.edu.au/about/graduate-school-health/genetic-counselling/news/demand-genetic-counsellors-grows>

The aim of the research was to determine UKGCs opinion regarding ‘the psychosocial component of the UKGC remit in the new genomics era’. In the UK, the debate continues regarding the level of counselling skills required by genetic counsellors and the centrality of the counselling activity to the effectiveness of genetic counselling sessions. A high value was placed on counselling skills and the benefits to patients and families from the counsellors’ commitment to CPD of their skills. Benjamin et al. (2020) found that participants valued their particular specialist knowledge, emphasising their unique selling point of skills in communication, counselling and psychosocial assessment. They acknowledged that other scientific and healthcare professionals were uncertain regarding the role and remit of genetic counsellors and it was important to improve this and awareness of the profession. To ensure that genomic technology leads to patient benefit, there needs to be an ongoing commitment of the whole healthcare multidisciplinary team, which includes the voice of genetic counsellors (Benjamin et al., 2020, p. 63). It was recognised that genetic counselling would have to develop new and innovative ways of counselling and communicating with patients and professionals by embracing technology such as video and teleconferencing and other communication applications.

Key skill set

“Equipping students with open eyes and listening ears may be the single most important thing we can do to prepare the genetic counselling workforce of the future to provide the best possible care” (McEwen & Jacobs, 2020a). McEwen and Jacobs argue that it is important for individual practitioners and the profession to reflect on, write, and constantly review their philosophy of practice (McEwen & Jacobs, 2020b). Reflective practice is included as a core competency of HGSA requirements. As the roles and scope of practice for genetic counsellors expand and diversify, it is increasingly important to understand, own, and retain the core values and principles as individual practitioners and as a profession. McEwen and Jacobs (2020) believe it is vital client-centred practice that remains at the heart of genetic health care. Recognition of the importance of maintaining a patient-centred service remains fundamental to the development of appropriate consent models, management of uncertainty (Thomassen Hammerstad et al., 2020), and the provision of psychosocial support.

Brett et al. considered the applicability of existing genetic counselling competencies to help manage emerging counselling issues (Brett et al., 2018). Counselling issues included a reappraisal of how genetic counsellors manage hope in the genomic era, informed consent for secondary use of genomic data, clinical reanalysis of genomic data, unexpected or unsolicited secondary findings, and trio sequencing. In their Singaporean study, Yuen et al. found significant improvement in empowerment in patients who received cancer genetic counselling, (e.g. patients felt better equipped to navigate educational, financial and social resources available) while also revealing a need to cultivate hope and ameliorate negative emotions in patients during genetic counselling (Yuen et al., 2020).

Earlier literature identified the challenge around regulation and registration (e.g., Dwarthe et al., 2019; Kurti et al., 2017) but now with national self-regulating regulation and the work being undertaken by HGSA around statutory endorsement, protected titles and funding, there are potentially more opportunities for autonomous practice and Medicare benefits.



Dwarthe et al. explored genetics practitioners’ (Australia and UK) current experience with panels and genomic tests and the associated evolution of genetic counselling practice. Some key themes arising from their semi-structured interviews included:

- Role delineation (current roles, future roles, and the influence of increasing complexity)

- increasing recognition and responsibilities and importance as a member of multi-disciplinary teams (MDT)
- greater specialism coinciding with mainstreaming, enabling genetic counselling to upskill in a specific area of practice, however, ongoing links between genetic counselling and specialist clinical genetics services were viewed as essential to maintain expertise, supervision, and professional development, especially for new graduates
- Evolving spectrum of practice
 - although there might be blurred boundaries between research and clinical services and issues around informed consent and return of results strategies, it was reported that the essence of genetic counselling and the core skills required by genetic counsellors were the same
- Policy and governance needs (equality of access; achieving consistent variant interpretation, reporting, and responsibility for review; managing incidental findings; and professional regulation for Australian genetic counsellors).

Multidisciplinary teams (MDT)

Similar to the views of McEwen and Jacobs (2020), the Dwarte et al. study indicates that genetic counselling practice and the essential role of facilitating informed consent are evolving but remain patient-centred, with core skills underpinning practitioners' capacity to adapt (Dwarte et al., 2019). The value-add and unique contribution of genetic counsellors in MDTs included case management, holistic care, accessibility and continued support, especially as advocates for patients and families. Forbes Shepherd et al. found that genetic health professionals were key facilitators of psychological support and reproductive advice for adolescents and young adults (AYA) with Li–Fraumeni syndrome (LFS), a rare cancer syndrome, significantly more so than oncology health professionals. However, they had little knowledge of specific support groups able to provide peer support, and options for AYA-specific services were limited for asymptomatic young people, as many are currently geared toward AYAs affected by cancer. Forbes et al. concluded that youth-friendly models of care are still emerging in clinical genetics, and the workforce may need formalised training and resources to help guide them (Forbes Shepherd, Keogh, Werner-Lin, Delatycki, & Forrest, 2020).

With their breadth of knowledge across and between genetic conditions, their understanding of the significance of a genetic test result and their experience in 'whole family' care, genetic counsellors are a key professional group to support mainstream practitioners deliver holistic genomic healthcare (Patch & Middleton, 2019, p. 288). As part of the MDT, genetic counsellors may have a role acting as a communicator between the interpreting laboratory and the clinician responsible for the MDT. Patch and Middleton (2019) suggest that they could also potentially connect, mentor and support a group of specialist nurses or allied clinicians all providing expert care in their own speciality and be the link person between different branches of the same family, when there are multiple diseases present. Within one setting they may also be able to overlay their genomic knowledge onto many different specialties again encouraging mainstreaming of genomic medicine. In the future, genomics will diffuse throughout the healthcare system and be relevant to the life-course of more patients and their families. This could be accompanied by diffusion of the specific skills of genetic counselling with competent health professionals supported by genetic (genomic) counsellors (Patch & Middleton, 2019, p. 289).

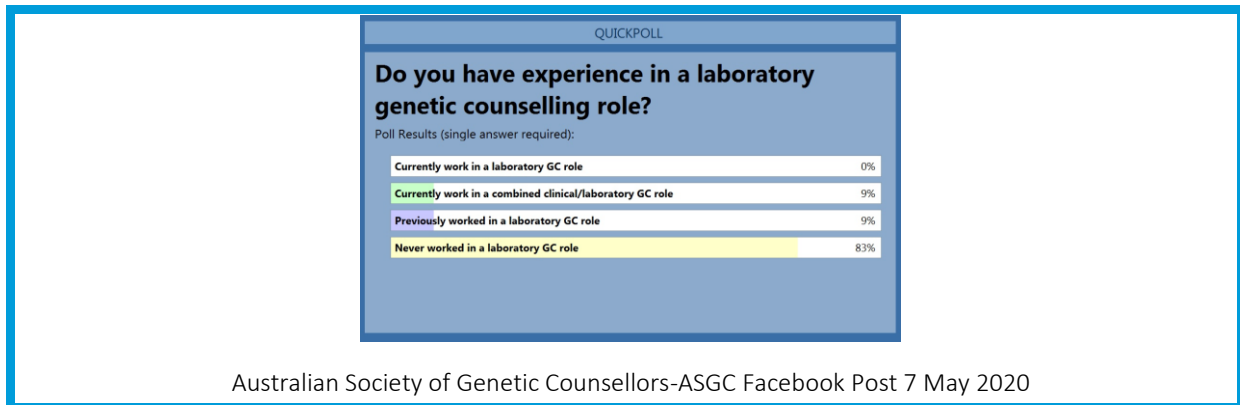
Awareness of role

Vuong et al. explored perceptions of genetic counsellors about the changing genomic landscape. Interim data presented at the 42nd Annual Scientific Meeting of the HGSA indicated that while they were cognisant of the significance of genomics to patients, patients may not see a difference between genetics and genomics. They noted overlap between research and clinical practice ('It's an interesting time for the profession ... there're going to be quite diverse roles') and perceived a lack of recognition of the genetic counsellor skillset and contribution ('I find myself having to advocate ...for genetic counselling as a profession').

Laboratory settings

Employment of genetic counsellors within mainstream health care services in order to facilitate ethical and appropriate genetic testing is occurring internationally (Shugar et al., 2017) and in Australia (Barlow-Stewart et al., 2015). Internationally, genetic counsellors are increasingly being employed in laboratory settings and are

involved in variant curation although this is not currently common in Australia; Dwarte et al. found that genetic counsellors in their study were split on their views about scope in this area. Participants highlighted a need for ongoing supervision and maintenance of professional expertise, by preserving links to a genetics department in a public hospital while working in mainstream services. The practice implications of greater specialism, the potential for incidental findings outside a genetic counsellor’s area of expertise, and service delivery models for mainstreaming, are required to promote effective integration of genetic counsellors within these services.



Service Delivery Models (SDM)

Mainstreaming of genomic testing will increasingly extend practice opportunities, leading to new genetic counselling positions within non-genetics services (e.g., cardiac and neuroendocrine clinics) or private clinics. Genomic technologies are also likely to differentially impact distinct specialisms, and one approach will not sufficiently meet the needs of all services (Dwarte et al., 2019, p. 385).

Genetic Counselling Assistants

The genomic era may increase time pressures on an already insufficient genetic counselling workforce such as in Canada (Shugar et al., 2017) and also in Australia (Dwarte et al., 2019; Kurti et al., 2017). However, delegation of some tasks offers a solution to overcoming workforce shortages. Dwarte et al. also reported that both Australian and UK participants in their study highlighted recent changes to clinical service structures promoting opportunities for appointments led by genetic counsellors (Dwarte et al., 2019).

The role of the genetic counselling intake assistant has been introduced in clinical genetic services across Australasia during the past few years. The ASGC believe that genetic counselling intake assistants are an important part of the genetic counselling team and can assist with effective and efficient genetic counselling (Human Genetics Society of Australasia, 2017). The introduction of the genetic counselling intake assistant role has been driven by the need to manage the increasing demand for genetic counselling services and the need to optimise the effectiveness, capacity and productivity of the genetic counselling workforce. Based on their US-based review, Hnatiuk et al. reported that genetic counselling assistants have the potential to address the high demand for genetic counsellors by promoting task-sharing, increasing genetic counsellor efficiency, and allowing for higher level duties, patient volumes, and efficiency to be optimised by genetic counsellors (Hnatiuk, Noss, Mitchell, & Matthews, 2019). It is important to note that the role of the assistant is not as a replacement to the genetic counsellor but a role that can support their work.

Telehealth services

Previous studies have highlighted both the utility and difficulty of implementing telegenetics services (Greenberg, Boothe, Delaney, Noss, & Cohen, 2020; Vrečar, Hristovski, & Peterlin, 2017). Some issues such as technological difficulties, communication barriers, and reimbursement limitations have changed with the need to accommodate new healthcare delivery methods in response to the COVID-19 pandemic. Bergstrom et al. demonstrated the ability of genetic counsellors to rapidly adapt to providing remote care in New York State via telegenetics, i.e., telephone and video (Bergstrom, Brander, Breen, & Naik, 2020). Despite general satisfaction with telegenetics under these conditions, most participants expressed a preference for in-person consultations.

The findings of their study support a hybrid model of in-person and remote healthcare delivery options tailored to patient and provider preferences (Bergstrom et al., 2020).

Hooker et al. reported that genetic counselling services in rural areas of North America are increasingly provided remotely via telemedicine, with 59 per cent of genetic counsellors in direct patient care in 2018 reporting providing services by phone and 19 per cent using web or video services to deliver care (Hooker et al., 2020). Vrećar et al. also reported that patient experiences in telegenetics show high levels of satisfaction (Vrećar et al., 2017).

Boothe et al. report that there is strong interest among genetic counsellors in the US learning about and implementing innovative SDMs such as telephone and group genetic counselling, telegenetics to improve access and efficiency in response to the increased demand on genetic services (Boothe, Greenberg, Delaney, & Cohen, 2020; Greenberg et al., 2020). Utilising outcomes measures and incorporating them into the evaluation of SDMs can result in beneficial research into the efficacy of new SDMs. For example, exploring the cost savings related to having a genetic counselling assistant in specialty areas other than cancer. In addition, there will be a push toward increasingly innovative models of services delivery such as the incorporation of chatbots for consent and other tasks (Schmidlen, Schwartz, DiLoreto, Kirchner, & Sturm, 2019).

Remote access

A survey-based study by Patel et al. was designed to determine whether access to remote genetic counselling impacts physician decision-making for appropriate patient selection, genes tested, and clinical management. They found that community-based breast specialists in the US were assessing risk and generally using guidelines to select appropriate patients for genetic testing. Remote genetic counselling support helps physicians choose the best gene panel test, aids in counselling challenging cases, and impacts clinical management. It was reported that remote genetic counselling appears to be an efficient use of this valuable resource and may provide a model for "as needed" or "on demand" genetic counselling as genetic testing volume and use of expanded panels grows rapidly (Patel et al., 2017).

Group counselling

Cloutier et al. explored group genetic counselling as an alternative service delivery model for women with a positive prenatal screening result (Cloutier et al., 2017). Both group and individual genetic counselling encounters significantly decreased patient anxiety, increased perceived personal control, decreased decisional conflict, and increased knowledge. Patient satisfaction was high following both methods. However, anxiety was significantly decreased in women who received individual genetic counselling compared with group sessions. It was suggested that group genetic counselling followed by the option of brief individual genetic counselling appears acceptable to women in a high-risk prenatal screening population. The findings support an alternative service delivery model for prenatal genetic services that could optimize the utilization of genetic counselling resources.



Information Technology

With the development of precision medicine, the use of health information technology (IT) platforms are important in the delivery of services across the cancer care continuum (Allen et al., 2020). Allen et al. (2020) conducted a survey among 128 board-certified cancer genetic counsellors in the US evaluating the use of 10 health IT tools and perceived barriers to adoption. Their findings indicate that addressing barriers to use and adoption of health IT may allow for expansion of these tools among cancer genetic counsellors. Integrating health IT is critical for enhancing cancer genetic counsellors' capacity to address patient needs and realising the potential of precision medicine.

Direct-to-Consumer Services

The potential rise in direct to consumer private genetic testing (DTCGT) services has been identified as a significant threat to the workforce and services (Benjamin et al., 2020). The increasing popularity of direct-to-consumer genetic testing and issues concerning technical validity and interpretation is reported to be causing a material impact on publicly-funded Australian genetics services (Millward et al., 2020). Almost half of Australian services reported taking clinical actions for at least one DTCGT-related referral, including risk-surveillance and cascade testing of family members. This demonstrates the appropriate downstream clinical management which can follow valid DTCGT-related results.

Nisselle et al. found that nearly two-thirds of genetic counsellors in clinical roles reported that patients asked them for information about or assistance with direct-to-consumer personal genomic tests. These respondents also reported the frequency of performing sequencing tasks in their practice, with 48.6% incorporating at least one aspect into their practice. They reported WES/WGS added approximately 2.75 hours extra in total workload per patient compared with the time needed for standard genetic tests. Clinical genetic counsellors are currently involved in every aspect of testing and indicated that genetic counsellors should continue to perform a broad range of tasks. Interviewees explained that their current involvement in test-related tasks was underpinned by their desire to understand genomic testing processes, thereby providing better counselling and support for their patients. This was seen more as educating themselves around a new testing technology, rather than a wish to transition into laboratory genetic counselling roles in the future.

Cultural Responsiveness

The provision of culturally responsive healthcare is essential best practice. Aboriginal people have a higher incidence of some genetically determined conditions however their overall use of specialist services is 43 per cent lower than for other Australians (Elsun et al., 2020). This reflects in part the challenges faced accessing specialist services in remote areas. Difficulties are amplified when cultural aspects that may influence or limit engagement with genetic health services are also considered (Kowal, Greenwood, & McWhirter, 2015). Elsum et al. describe client and staff perspectives of a model of clinical genetics services provided by the MJD Foundation (Machado-Joseph Disease) in geographically and culturally complex contexts within the Northern Territory (Elsun et al., 2020). The model: a) is client led; b) develops shared understanding where a variety of explanations for disease causation are accepted by the Foundation, acknowledging that the biomedical explanations and traditional cultural understandings can exist concurrently; c) is predicated by relationships, continuity and trust between the service providers and their clients, and d) involves a family approach. It was reported that by incorporating these principles and taking a community-based, person-and family-centred approach, mainstream specialist services including clinical genetics services may improve engagement with Aboriginal people and provide more comprehensive care (Elsun et al., 2020). Continued engagement within communities is an essential first step in designing client led service delivery and services must be flexible enough to accommodate diversity of Aboriginal Australians' cultural values and adapt at a local community level.

It is also worth noting that there may be some concerns relating to genetic testing and Aboriginality however the Inquiry into Kinship and Identity²⁹ considered that under no circumstances should any person be required to undergo genetic testing to establish their Aboriginal descent. While genetic testing technology may be used to re-establish links between individuals and their Aboriginal family (such as links that were severed by government policies that promoted separation and assimilation), these tests and information are only to confirm direct kinship relationships and not any determination of a person's culture, race or ethnicity.

Workforce Diversity

The census of Australian genetic counsellors and clinical geneticists (Nisselle et al., 2019) found that almost all genetic counsellors are female (96.3%) and information from the Ministry indicates that the percentage of Aboriginal genetic counsellors is less than two per cent.

Increasing the number of Aboriginal practitioners would enhance the provision of culturally responsive care and support self-determination for Aboriginal communities in genetic health (Hodgson & Browne, 2019). The Victorian Government Department of Health and Human Services has funded a project to encourage and facilitate Aboriginal engagement in the genetic counselling training pathway at UniMelb. The project aims to address the entry, financial and employment transition barriers that hinder Aboriginal students' participation in becoming a certified genetic counsellor (Hodgson & Browne, 2019).

Workforce diversity in the US has remained static for over 50 years. A minority Genetic Professionals Network has been established to support recruitment and mentorship as well as providing support, education and mentor matching for current practising genetic counsellors and students (Mann, 2020).

Mental Health and Primary Care

Although no genetic tests are clinically useful in establishing, refining or excluding a psychiatric diagnosis, Hippman et al. suggested that genetic counselling should be considered for patients with serious mental illnesses (i.e., schizophrenia, schizoaffective disorder and bipolar disorder) (Hippman et al., 2016).

There is potential for the development of a primary care genetic counselling model, in which GPs are responsible for communication (and associated counselling) of basic test results, and a part-time onsite genetic counsellor takes on more complicated cases. This service delivery model, it was reported, works well for specialist nurses and allied health professionals, especially in larger practices. There was general agreement amongst clinical geneticists that GPs typically do not possess the requisite knowledge and skills to take on more complex cases, and that, at minimum, primary care models for genetic counselling should incorporate a certified genetic counsellor, one who has regular, formal supervisory contact with a clinical geneticist. This link to a geneticist would be necessary for the ordering of specialist tests from accredited laboratories (Kurti et al., 2017).

How do genetic counsellors identify their role within the NSW Health system/org structure?

The literature does not provide any specific information on how genetic counsellors identify their role specifically within NSW Health. However, some papers point to the prevailing view of these roles as noted in previous sections.

The Urbis review consultations identified the genetic counsellor workforce to be an adaptable group that provide a valued and important service across the NSW health system.

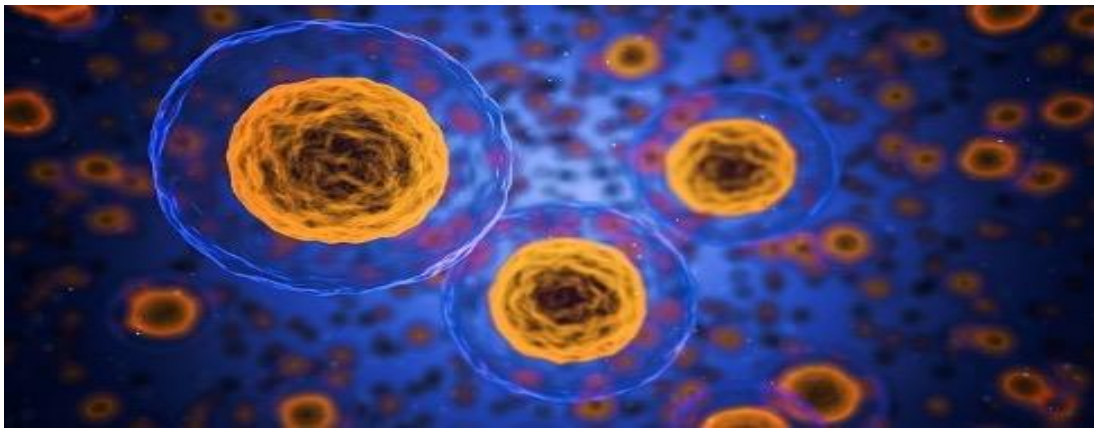
Consistent with the results of their literature review (Kurti et al., 2017), stakeholder feedback suggested that the tasks routinely undertaken by genetic counsellors, and the associated clinical governance and supervisory arrangements, vary significantly across the NSW health system. Despite this variation in the service delivery

²⁹ <https://www.alrc.gov.au/publication/essentially-yours-the-protection-of-human-genetic-information-in-australia-alrc-report-96/>

models, the specific tasks performed by genetic counsellors appeared to rarely fall outside the domains of genetics (including ethics and informed consent), counselling, and multidisciplinary team care, and most public sector counsellors seem to work across all three domains.

A US-based survey of undergraduate students regarding information related to their awareness, perceptions, knowledge, and interest in genetic counselling found that factors commonly reported as attractive about the field included direct patient care, the variety of roles available, cultural competency and psychosocial training, and helping others (Gerard et al., 2019).

Increasingly, genetic counsellors are called upon to succinctly state the value they add and to articulate the difference between genetic counselling as provided by genetic counsellors and genetic counselling as provided by other disciplines (Athens et al., 2017). As genetic counsellors embrace the opportunities of increasingly diverse positions in healthcare systems, it is crucial that they are confident in their professional identity (McEwen & Jacobs, 2020b). Educators in the genetic counselling discipline at UTS “recognise and celebrate the many emerging opportunities for genetic counsellors, including research and academic roles, laboratory genetic counsellor roles, policy and leadership roles and roles that will use technology in new ways to provide genetic counselling care.” (McEwen & Jacobs, 2020b, p. 4). They believe that a philosophy that holds at its heart the well-being, safety, care, and thoughtful consideration of the individuals and families who live with inherited conditions is directly applicable to all these roles and to those roles that are yet to emerge.



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Appendix 1: Professional Organisations and Regulation for Genetic Counsellors

The Human Genetic Society of Australasia (HGSA) was formed in 1976, and is a society of 1000 professionals from clinical, laboratory and academic specialties in Human Genetics. Genetic counsellors comprise the largest professional group in the HGSA.

In 1993, the Australasian Society of Genetic Counsellors (ASGC) was formed as a 'special interest' group within the HGSA. The ASGC represents over 280 members providing genetic counselling or members of the HGSA working in related areas across Australia and New Zealand. The majority of the members are either training as or are certified genetic counsellors. The ASGC is a member of Allied Health Professions Australia (AHPA).

In 1989 the HGSA appointed a Board of Censors for Genetic Counselling (the Board) to certify genetic counsellors in Australia and New Zealand. In 1990, the HGSA ratified the first Guidelines for Training and Certification in Genetic Counselling, to be administered by the Board.

The HGSA, as the regulatory body for genetic counsellors, is a member of the National Alliance of Self-Regulating Health Professions (NASRHP).

NASRHP is the national peak body representing self-regulating health professionals in Australia and is supported by the Australian Department of Health. NASRHP provides a quality framework for allied health professions not eligible for registration through AHPRA. Member organisations must meet benchmarked standards for practitioner regulation that are aligned with AHPRA standards and satisfy the National Code of Conduct for health care workers.

The HGSA Professional Issues for Genetic Counselling Working Party was established in June 2017, to provide strategic leadership for the professional recognition of genetic counselling. In March 2020, the HGSA Board of Censors for Genetic Counselling was granted full NASRHP membership for the regulation of genetic counsellors in Australia.

As part of NASRHP membership, and in line with other registered and regulated health professions, the HGSA now publishes an online register of genetic counsellors who are engaged in the regulatory process, which includes active participation in (provisional) or completion of HGSA Board Certification and ongoing CPD.

Appendix 2: Challenges

The following table summarises the challenges facing the NSW genetic counselling workforce now and into the future identified in the SAX Evidence Check (Barlow-Stewart et al., 2017).

<i>New and emerging challenges, as well as current and ongoing challenges that relate to this area</i>
<i>Impact of new technologies on genetic counselling practice</i>
<ul style="list-style-type: none"> ○ Genomic testing ○ Impact on genetic counselling
<i>A changing clinical paradigm to meet increasing demand</i>
<ul style="list-style-type: none"> ○ Mainstreaming of genetic and genomic testing ○ Increased demand requires increased workforce
<i>Challenges specific to the field of genetic counselling and broader relevant challenges facing small but critical health professional workforces</i>
<i>Challenges and barriers to training and certification, and building the workforce</i>
<ul style="list-style-type: none"> ○ Limited student numbers in the Master's courses ○ Training places to provide opportunities for Board certification ○ Reciprocity of training internationally ○ Cancer genetic counsellors and cross training ○ Clarifying the ambiguity in relation to certification and the award (largely addressed with regulation and recent policies on scope of practice)
<i>Need for increased diversity within the profession</i>
<i>The increased demand on genetics services and genetic counselling workload as a result of increased awareness about genetic testing</i>
<ul style="list-style-type: none"> ○ The Angelina Effect ○ Community awareness and expectations
<i>Traditional models of genetic counselling provision will not meet the needs of new paradigms of care</i>
<i>Expanding the role of genetic counsellors</i>
<i>Public health impact</i>
<i>Challenges/changes related to key partners</i>
<ul style="list-style-type: none"> ○ Clinical geneticists ○ Non-genetics trained medical specialists
<i>Continuing education needs of genetic counsellors and genetic counsellors as educators of non-genetics trained health professionals</i>
<ul style="list-style-type: none"> ○ Upskilling the genetics workforce in the genomics era ○ Educating non-genetics health professionals and genomics
<i>Challenges resulting from changes in technology, science, policy, costs, and service delivery models and regulatory frameworks</i>
<i>Increasing impact of new technologies on genetic counselling practice and a changing clinical paradigm</i>
<i>Existing models of consent need to evolve</i>
<i>Need for registration of the profession</i>
<i>Costs</i>
<ul style="list-style-type: none"> ○ Medicare funding ○ Educating non-genetics professionals ○ Board certification
<i>Service delivery models (e.g. telehealth)</i>
<i>Need for national harmonisation in policy governing delivery of genetic counselling in the genomic era</i>

Appendix 3: Participating stakeholders

We would like to acknowledge and thank the many contributors to this project and wish all NSW Health genetic counsellors every success with their future workforce planning efforts.

- Alison McEwen UTS
- Brenda Greyling NSLHD
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- Jessica Duffy ISLHD
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- Leonie Noon WNSW
- Lisa Smith NBMLHD
- Lorraine Hodgson NNSWLHD
- Louise Lynagh St Vincents
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- Lynley Donoghue NBMLHD
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- Ron Fleischer SLHD
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