



Implementation Plan

National Health Genomics Policy Framework

Driving National Action

2018–2021

Implementation Plan—National Health Genomics Policy Framework

978-1-76007-362-6 (print version)

978-1-76007-363-3 (online version)

Publications Number: 12145

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Introduction

This is the Implementation Plan for the 2018–2021 National Health Genomics Policy Framework (the Implementation Plan). The National Health Genomics Policy Framework (the National Framework) was developed by the Commonwealth and the states/territories under the Australian Health Ministers' Advisory Council (AHMAC) governance arrangements. It was agreed by the Council of Australian Governments (COAG) Health Ministers in November 2017.

The National Framework is a blueprint for coordinated action by governments, health professionals, non-government organisations and industry to work in partnership to embed genomics in the Australian health system. This Implementation Plan (as with the National Framework) is directed at decision-makers and policy-makers at the national, state/territory and health service levels.

Some states and territories have genomic policy strategies that align with the National Framework; however, this is the first time in Australia that a national strategy articulates short to long term goals across a number of key policy areas that impact on the Australian health system and health outcomes. The National Framework provides an overarching framework for state/territory strategies and local hospital networks. The Implementation Plan provides some examples of actions at state/territory level.

The purpose of the National Framework is to:

- establish a high-level policy document to give coherence to, and guide government activity across, public genomics policy (noting that the focus of the first iteration is health care applications that are informed by, or based on, human genetic or genomic testing);
- drive improved performance of mainstream genomic services in delivering better health outcomes;
- give visibility to the ethical, legal and social issues associated with genomics and ensure their inclusion in the development and implementation of all public policy and research; and
- provide national leadership for embedding genomics in the Australian health system.

The Implementation Plan has been developed by the Commonwealth Department of Health under the guidance of an AHMAC jurisdictional reference group, reporting through the Clinical Principal Committee, to support the National Framework.

This implementation plan should be read in conjunction with the National Framework and the associated Supplementary Information.

The National Framework documents provide context, detail terminology, and signal the policy intent of the implementation plan.

BACKGROUND

The National Framework aims to help people live longer and better lives through harnessing the benefits of human genomics in a cost-effective, equitable, and ethical way in the Australian health system. It sets the direction for a nationally coordinated approach to genomics that avoids duplication of effort and leverages current activities.

The National Framework identifies five key strategic priority areas for increased national effort:

1 Person-centred approach	Delivering high-quality care for people through a person-centred approach to integrating genomics into health care.
2 Workforce	Building a skilled workforce that is literate in genomics.
3 Financing	Ensuring sustainable and strategic investment in cost-effective genomics.
4 Services	Maximising quality, safety and clinical utility of genomics in health care.
5 Data	Responsible collection, storage, use and management of genomic data.

It also recognises that these priorities must be underpinned by clear governance arrangements; a responsible approach to ethical, legal and social issues; and stakeholder engagement.

SECTOR CONSULTATION

A broad range of stakeholders were identified and consulted with extensively on the development of the National Framework. Public stakeholder forums were held in Sydney and Melbourne, as well as an expert roundtable in December 2017 on the draft Implementation Plan. These forums, together with written submissions from individuals and from organisations representing researchers, consumers and health care professionals, have informed the Implementation Plan for the National Framework.

TRANSLATING THE NATIONAL FRAMEWORK INTO ACTION

The Implementation Plan acknowledges that involving all governments and the wider community is pivotal to addressing the challenges associated with harnessing the benefits of genomics for all Australians. The Implementation Plan establishes the groundwork for the National Framework. It proposes strategic projects and actions that will drive progress over the longer term while implementing high-priority actions in the short term. As the National Framework has a long term vision, some actions are expected to go beyond its initial three-year life span.

The actions in this Implementation Plan are pitched at a high level to build the foundations to achieve the outcomes identified in the National Framework. Each action is likely to require further detailed planning; in some cases this may involve a series of project-specific activities that will contribute to the aims of the implementation action. The lead organisation or group nominated in the Implementation Plan for a specific action will be responsible for developing the more detailed project plan, including, where necessary, further stakeholder consultation.

The Australian Council of Learned Academies (ACOLA) report *The Future of Precision Medicine in Australia* (January 2018) recognises that Australia's clinical and research efforts in genomics will act

as a platform for the development of personalised medicine for all Australians. With further discovery there will be greater opportunities for investment that will drive improved health outcomes for all Australians. The ACOLA report recognises that appropriate policy (with a focus on ethical, legal and social issues) will assist in harnessing precision medicine and that, while there will be costs in establishing the infrastructure required for genomics, these may eventually be offset by improved health in the community, new employment opportunities, and growth in the innovation sector.

The Commonwealth and the states/territories are already making substantial investments in genomic health care, including clinical and health system research streams. While no additional funding is available at this time to take forward new proposed projects and actions under the Implementation Plan, governments are expected to consider these as priorities for any further investment as resourcing permits.

Some states/territories are developing their own implementation plans that will reflect their priorities, but they will also contribute to delivering on outcomes under the National Framework. These implementation plans are expected to outline the actions already being taken and reflect new initiatives being undertaken to support key national priorities. Given the high level of activity occurring across governments and research organisations, it will be valuable for all stakeholders to share and adopt best practice.

PURPOSE AND SCOPE OF THE IMPLEMENTATION PLAN

The Implementation Plan incorporates activities being undertaken across various sectors to encourage and enable collaboration and information sharing. It is a high-level plan aimed at identifying the actions that need to be taken nationally to maximise health outcomes for all Australians. While actions have been assigned within each strategic

priority area, some actions will contribute to multiple strategic priority areas. Most actions relating to ethical, legal and social issues are considered under Strategic Priority 1, but they are intrinsically linked to all of the strategic priority areas.

ROLES AND RESPONSIBILITIES

The Commonwealth and state/territory governments have specific roles and responsibilities across the range of health policies and programs that involve, or are becoming increasingly influenced by, human genomics. The National Framework does not change the nature of these roles and responsibilities but seeks to create a more cohesive approach across the Commonwealth and state/territory governments. The National Framework recognises that coordinated and comprehensive planning is required between all levels of government and across a range of portfolios. The National Framework exemplifies this approach, with federal and state levels of government involved in both its development and its implementation.

While the National Framework is the responsibility of the Commonwealth and the states/territories under the AHMAC governance arrangements, the work and cooperation of research organisations, public and private pathology laboratories, health care professionals and organisations, educational leaders and the private sector will be integral to achieving the overall vision of the National Framework. Some of the key activities undertaken by these stakeholders are reflected in the Implementation Plan.

It is expected that detailed work streams and project plans will be developed, expanding on each of the strategic priorities. More detailed project plans will expand on *how* the implementation actions are to be taken forward.

NATIONAL AND INTERNATIONAL PARTNERSHIP AND COLLABORATION

It will be important that, wherever possible, implementation actions align with or build on international best practice and evidence. This will be foundational in supporting international engagement across the strategic priority areas for action.

The Implementation Plan seeks to build on existing efforts by organisations in clinical, research and industry settings across Australia and internationally. To the extent possible, the aim is to identify and adapt local/international best practice and adopt it nationally.

TIME FRAMES OF THE IMPLEMENTATION PLAN

Indicative time frames for completion have been proposed for each implementation action:

- short term (12–18 months)
- medium term (18–24 months)
- long term (more than 24 months).

These time frames indicate the expected length of time required to complete the proposed action. Some actions that are flagged as long term may extend beyond the life span of the first iteration of the National Framework. Ongoing actions are those which may be completed in the short to long term, but will need to be regularly revisited. The prioritisation and start dates of actions (guided by the designation of short, medium and long term) will be dependent on decisions made by the project leaders under the governance arrangements to be put in place.

The proposed time frames indicate the expected time line for completion of an implementation action—not when work on an action is expected to commence.

Governance

Effective governance is essential for driving and coordinating implementation of the National Framework. To ensure that all governments are involved and work is taken forward in a cohesive way, it is appropriate for the governance arrangements to be established under the AHMAC structure.

AHMAC is the advisory and support body to the COAG Health Council (CHC). It operates to deliver health services more efficiently through

a coordinated or joint approach on matters of mutual interest. AHMAC is responsible for providing effective and efficient support to CHC by:

- advising on strategic issues relating to the coordination of health services across the nation and, as applicable, with New Zealand; and
- operating as a national forum for planning, information sharing and innovation.

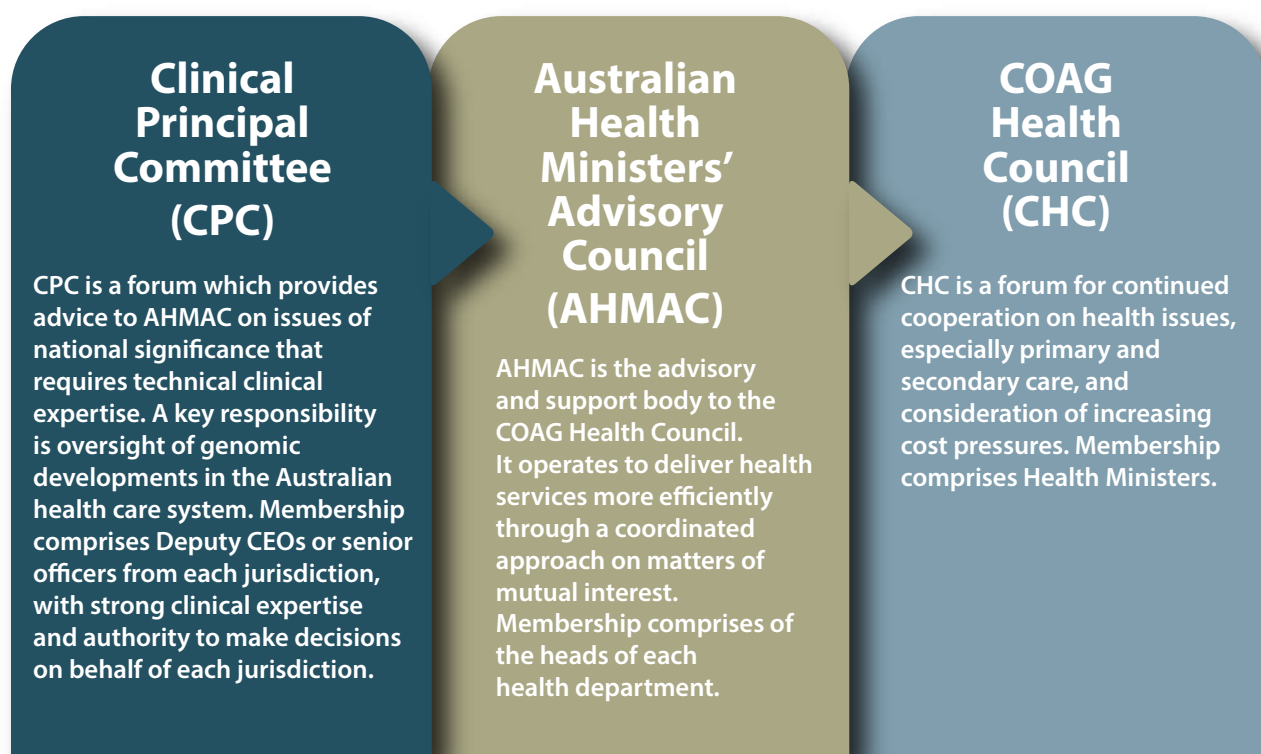


Figure 1: Explanation of governance structure

AHMAC has four principal committees, which manage the business of AHMAC and provide advice. One of these is the Clinical Principal Committee (CPC). AHMAC membership includes chief executives from all departments of health, while CPC membership consists of senior medical officers. Depending on the nature of the implementation action, it may be relevant for other principal committees (for example the Health Services Principal Committee) to be involved in noting or endorsing particular implementation actions.

Governance arrangements are to be consultative and transparent. This includes openly sharing and, where practicable, inviting comments on documentation such as terms of reference, project plans and progress reports. Where possible, co-design principles will be adopted in driving specific activities under each action. AHMAC and CPC will make decisions on how, and from whom, they seek advice on an as-needed basis.

GOVERNANCE—DIRECTIONS AND DECISIONS

National action	Roles	Time frame for completion	Lead responsibility
Action i: Governments will establish governance arrangements through the AHMAC structure to provide advice (as informed by consultations) on the implementation of the National Health Genomics Policy Framework.	The National Genomics Policy Framework Project Reference Group will provide advice to CPC on the options available.	Short term	CPC
Action ii: Governments will evaluate the National Health Genomics Policy Framework and the effectiveness of governance arrangements. This evaluation will begin in 2020 and be completed during the life of the framework. It will be completed in time to inform the future directions in health genomics policy.	The Commonwealth will commission an independent evaluation, including development of an evaluation plan. AHMAC will determine the need for, and focus of, any further iterations of the Framework, based on the findings of the evaluation plan.	Long term	AHMAC/ Commonwealth

ACCOUNTABILITY—MEASURING AND REPORTING

National action	Roles	Time frame for completion	Lead responsibility
<p>Action iii: Governments will develop a national system performance framework* to guide and monitor ongoing efforts to appropriately embed genomics in the health system in an equitable, cost-effective, efficient and ethically informed way.</p> <p>In order to improve trust in genomics and promote accountability for service delivery at a local level, the performance framework should also indicate key metrics that will encourage and measure engagement with genomics across public and private health providers as well as the community.</p>	CPC will commission the development of a performance framework.	Short term	CPC
<p>Action iv: Governments will request that CPC deliver an annual report for presentation to health ministers on progress in implementing the Framework.</p>	CPC will ensure that the governance arrangements provide for development of an annual report.	Short term—ongoing	CPC
<p>Action v: Governments will regularly review and update the Implementation Plan over its three-year life span in response to the annual reviews on progress, significant changes in the sector, and advances in genomic knowledge/technology.</p>	AHMAC will establish arrangements for a regular review of the Implementation Plan, and for advice to be provided on the need for the Implementation Plan to be updated.	Short term	CPC

* Performance framework

This framework is expected to include high-level indicators of change, as there is currently no nationally consistent dataset on which to build a robust and reliable evidence base. In the longer term, the National Stocktake of Genetic/Genomic Testing will create nationally consistent definitions and collection methods for longitudinal analysis of trends in the uptake of tests. As genomics becomes increasingly integrated across the health system, additional sources of data (including population health data) will also be used to inform and improve the performance framework.

The performance framework should align with any other performance framework guidance for elements of the health system developed through AHMAC or other government processes (such as the Health Performance Framework).

Implementation of Strategic Priority 1: PERSON-CENTRED APPROACH

Delivering high-quality care through a person-centred approach to integrating genomics into health care

CURRENT GOVERNMENT ACTIVITIES

Many initiatives to support person-centred care are under way nationally. Evidence-based guidance is also available to patients, consumers and health professionals, including the National Health and Medical Research Council guidance on genetic discrimination. Given the rapid growth of genomic knowledge and the shift in global attitudes and trends, it is appropriate that such guidance is subject to regular review.

Various policy, program and communication strategies operate at all jurisdictional levels to support people in the challenges and choices they may face when deciding on their health care. The need for genomic education of patients and families is widely recognised as being critical to maximising the potential benefits to patients while also managing expectations.

The Commonwealth and the states/territories are funding research through leading research bodies and consortiums that focus on a range of related issues including:

- examining issues in the context of genomic data sharing (including legal and non-legal barriers);
- considering the patient experience and ethical aspects;
- mapping existing materials; and
- piloting clinical genomics consent and research genomics consent processes that could be adopted nationally.

PRIORITY AREAS FOR ACTION

- 1.1 Improve support for individuals, and their families, to make informed choices about genomic testing, and take responsibility for those choices and related risks.
 - 1.2 Encourage appropriate referrals of genomic testing, that put the welfare and needs of the individual first, thereby avoiding unnecessary testing.
 - 1.2.1 Developing and promoting clinical practice guidelines and decision support tools for engaging with individuals on their personal context and health goals.
 - 1.3 Engage relevant community/patient advocacy organisations and consumers in discussions of the consumer experience, as well as on the ethical, legal and social issues of genomics.
 - 1.3.1 Developing community engagement strategies to promote an understanding of the application and impact of genomic advances in health care, including the gap between testing and treatment options.
 - 1.3.2 Exploring how the consumer experience can be captured and measured to inform priorities and establish a baseline.
 - 1.4 Promote public awareness and understanding of genomics, including through linguistically and culturally safe and appropriate information resources for targeted consumer groups.
 - 1.5 Identify barriers to equity of access and develop a national approach to address these, noting that access is multi-dimensional and includes location, cost, availability and appropriateness (including cultural acceptability). This includes, but is not limited to:
 - exploring barriers to the uptake of genomic services including the potential for discrimination (life insurance, employment, lifestyle, access to services etc); and
 - evaluating the delivery of genomic services in terms of being accessible, appropriate and culturally secure and responsive for Aboriginal and Torres Strait Islander peoples.
 - 1.6 Investigate how genomics data can be integrated with electronic health records to improve coordination of care, support better clinician decision-making and facilitate seamless clinical pathways.
 - 1.7 Explore the potential to develop integrated person and family-centred care delivered by multi-disciplinary teams, where appropriate.
 - 1.8 Identify and promote a standard model of consent that is sufficiently flexible to support a person's understanding of the potential implications of having their genome sequenced, familial aspects and decision-making about any secondary findings, as well as including provision for access by researchers if appropriate.
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IMPLEMENTATION ACTIONS

These actions are to support people being involved in, and central to, their genome-directed diagnosis, health care and treatment.

NATIONAL ACTION	TIME FRAME FOR COMPLETION	LEAD RESPONSIBILITY
ACTION 1: Engage with the Attorney-General's Department regarding the 2003 <i>Essentially Yours</i> report to explore reviewing key recommendations (noting the changing context since 2003) and implementing any new or revised recommendations. Priority is to be given to privacy legislation and genetic discrimination connected to risk-rated insurance.	Short term	Commonwealth
ACTION 2: Build on existing work to review current legislation that provides protections for the public, and seek opportunities to communicate its application to genomics.	Medium term	Commonwealth, states/territories
ACTION 3: A: Identify, map and collate people's views on genomics and the ethical, legal and social issues (ELSI) related to genomics, including engaging with Aboriginal and Torres Strait Islander peoples (consistent with the principles of the <i>National Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016–2026</i>) and other vulnerable populations to understand their perspective on ELSI. B: Use the information from 3A to inform the development of strategies and communications around ELSI, building on current initiatives where appropriate.	Short term—ongoing	AHMAC, Commonwealth, states/territories
ACTION 4: A: Build on existing work to develop and promote nationally consistent templates and guidance for consent. B: Use existing work to consider the role of consent models for health care and data-sharing purposes, including, but not limited to, dynamic consent. C: Develop and promote a national, principles-based approach to managing secondary and additional findings (be they incidental or deliberate), including consideration of medico-legal implications.	Short term—ongoing	CPC, Commonwealth
ACTION 5: A: Promote national consistency in content and terminology of genomics to improve public literacy, including ELSI definitions. B: Review existing materials and their effectiveness to identify gaps in people's literacy and experience. C: Work with patient and consumer advocacy groups to prioritise development of new materials for the public and seek to centralise existing and new materials through an online portal where the public can access trusted information on genomics. D: Identify opportunities to promote health literacy through community groups.	Short term—ongoing	CPC

Implementation of Strategic Priority 2: WORKFORCE

Building a skilled workforce that is literate in genomics

CURRENT GOVERNMENT ACTIVITIES

Genomic medicine presents a major workforce development challenge. In particular, there are distinct challenges for rural and remote communities seeking access to genomic services. Many states/territories are already taking action to better understand how the workforce needs to evolve to support genomics as an integral part of mainstream clinical practice. For example, a report commissioned by the New South Wales Government in 2017, *The Changing Landscape of the Genetic Counselling Workforce*, concluded that there is a need to clarify the qualifications for undertaking this role and for defining more clearly the place of genetic counselling within and across the health system.

The primary health care workforce is also expected to take on an increasing role in determining access, linking patients to appropriate genomic services, and helping patients understand and deal with findings.

The Commonwealth is funding research into mapping workforce needs (through audits, surveys, interviews etc.) 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 mathematicians, bioinformaticians, genomic and computer scientists, researchers, genetic counsellors and other allied health professionals in translating findings from a research environment into a clinical context.

PRIORITY AREAS FOR ACTION

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- 2.1 Improve the genomics literacy and capability of the health workforce through the development, delivery and ongoing maintenance of appropriate genomic education, training and skills.**

 - 2.2 Build the capacity for, and promote access to, a skilled and literate genomics workforce, through workforce strategies and planning at the national level.**

 - 2.3 Facilitate partnerships and networks to promote and support sharing of knowledge.**

IMPLEMENTATION ACTIONS

These actions are to upskill the broad health workforce through increasing capacity and capability in genomics and bioinformatics.

NATIONAL ACTION	TIME FRAME FOR COMPLETION	LEAD RESPONSIBILITY
ACTION 6: A: Map the current genomic workforce composition and seek to leverage current strategies or, where appropriate, develop new strategies to improve access to appropriate genomic services, noting the needs of vulnerable populations. B: Use existing and new workforce mapping to identify long term challenges to the genomic workforce and determine what supports and capabilities are necessary to ensure the equitable supply and distribution of a skilled workforce based on service need.	Short term	AHMAC, states / territories
ACTION 7: Develop and enhance genomic literacy for the broader health workforce, including through materials and training needs (including health communication training) of health sector staff working with Aboriginal and Torres Strait Islander peoples and other vulnerable populations.	Medium term	AHMAC, states/territories
ACTION 8: Engage with relevant professional bodies and colleges that oversee and inform postgraduate health workforce training, including continuing professional development.	Medium to long term	AHMAC, states/territories
ACTION 9: Build collaborative relationships between governments, professional bodies, clinical leaders (as champions or gatekeepers) and tertiary education providers to streamline and improve the integration of health genomics into curricula, including the feasibility of genomics (including ELSI) as a core competency for the provision of medical education.	Long term—ongoing	AHMAC, states/territories
ACTION 10: 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.	Short term—ongoing	CPC, Commonwealth

Implementation of Strategic Priority 3: FINANCING

Ensuring sustainable and strategic investment in cost-effective genomics

CURRENT GOVERNMENT ACTIVITIES

Health technology assessment (HTA) processes are applied in multiple contexts within the health system in order to assess the value of new and emerging health applications for public funding within Australia. The federated health system has led to the Commonwealth, states and territories employing different HTA processes. Some Local Hospital Networks also have their own processes for assessing new health technologies. The HTA process allows governments to assess whether a new health technology should be supported by public funding. If a new technology is considered to meet standards around safety, effectiveness and cost-effectiveness, a further decision on how, or through what funding mechanism, that technology is best supported still needs to be made by the relevant government authority.

The main reimbursement mechanism for the Commonwealth is the Medicare Benefits Schedule (MBS). The Commonwealth is taking a lead role in building capabilities and experience to support the development, submission and assessment of applications to the Medical Services Advisory Committee (MSAC) for funding of new genetic/genomic testing services through the MBS. Historically the focus through the MBS has been on single-gene tests, but massive parallel sequencing capabilities that allow for interrogation of multiple genes in a single test will challenge the existing assessment and funding mechanisms.

There is a collective effort by the Commonwealth and the states/territories to strengthen the evidence base for demonstrating the cost-effectiveness of genomic services by exploring and reporting on economic evidence that supports the integration of genomics into health care. This includes working with national and state-based alliances and other organisations, such as the Global Genomic Medicine Collaborative, to review evaluation methods and criteria for genomic tests.

PRIORITY AREAS FOR ACTION

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- 3.1 Consider genomics in the context of any broader review of health technology assessment to support national consistency.**
 - 3.2 Develop partnerships, funding and data sharing approaches for genomics that promote access to safe, efficient and cost-effective services.**
 - 3.3 Develop a national research agenda for genomics and identify opportunities to link to Commonwealth and state/territory research priorities.**
 - 3.4 Better understand the role of the private industry, and the opportunities for partnerships to support the development and sustainable application of genomic knowledge.**
 - 3.5 Collaborate across governments and stakeholders to maximise investments and reduce duplication of resources and efforts.**
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IMPLEMENTATION ACTIONS

These actions are to ensure that Australia's investment in genomic health care and research delivers actionable results that lead to people living better and longer lives.

NATIONAL ACTION	TIME FRAME FOR COMPLETION	LEAD RESPONSIBILITY
ACTION 11: Leverage existing mechanisms and processes to develop nationally cohesive approaches to Health Technology Assessment (HTA) of genetic and genomic applications that inform adoption of new technologies and processes for disinvestment where appropriate.	Short term	AHMAC
ACTION 12: Examine equitable financing and purchasing models to inform the appropriate integration of safe, effective, ethically informed and cost-effective genomic health care delivery.	Medium term	Commonwealth, states/territories
ACTION 13: A: Map current private and public sector research activities across jurisdictions. B: Leverage mapping from 13A to explore options to strengthen national and international coordination and planning of genomic research to inform the development of a national health genomics research agenda that will support improved health outcomes at an individual and population health level.	Short to Medium term	CPC
ACTION 14: Identify opportunities to foster commercial partnerships and engagement to drive innovation in advancing the national genomics effort.	Medium term—ongoing	Commonwealth, states/territories

Implementation of Strategic Priority 4: SERVICES

Maximising quality, safety and clinical utility of genomics in health care

CURRENT GOVERNMENT ACTIVITIES

There are a range of current government activities that focus on clinical utility, patient safety and cost-effectiveness.

The Therapeutic Goods Administration (TGA), within the Commonwealth Department of Health, is responsible for continuing to ensure the quality, safety and performance of genomic tests so that patients and clinicians can receive accurate and clinically significant test results. Regulatory approaches enable innovation in testing and timely market access to genetic/genomic tests that are safe and fit for purpose.

The Commonwealth and the states/territories are also supporting research to identify appropriate pathways for genomic research to translate into safe, effective, and cost-effective clinical application. The TGA and the National Health and Medical Research Council offer guidance and information on the regulation and use of direct-to-consumer genetic tests, which is subject to review and is updated as required.

The Standing Committee on Screening (SCoS) established under the CPC has responsibility for considering population-based genomic screening and other screening programs. SCoS is currently in the early stages of assessing potential options available for genomic screening.

PRIORITY AREAS FOR ACTION

4.1 Review and build on guidelines, regulations and standards to ensure genomic applications:

- are evidence-based;
- nationally consistent (where appropriate);
- demonstrate clinical utility; and
- align with agreed national ethical approaches.

4.2 Strengthen processes to identify, promote, monitor and report best practice in clinical genomics, including sharing of data and information.

4.3 Maximise genomics research opportunities that aim to resolve clinical uncertainty and improve quality and safety.

IMPLEMENTATION ACTIONS

These actions are to ensure that the use of genomics in health care is based on the best available knowledge, evidence and research and that the outcomes of treatment are used to help improve care.

NATIONAL ACTION	TIME FRAME FOR COMPLETION	LEAD RESPONSIBILITY
ACTION 15: A: Work with stakeholders to update guidance on genomic testing and research (including direct-to-consumer testing conducted to inform medical care). B: Recommend national adoption of guidance developed under 15A and work with stakeholders to explore options to improve reporting mechanisms.	Short term—ongoing	Commonwealth, states/territories
ACTION 16: Provide advice to SCoS (which reports to CPC) to inform a nationally consistent approach to a position on genomic population screening.	Short term—ongoing	Commonwealth, states/territories
ACTION 17: Support development and sharing of evidence-based clinical practice guidelines and decision support tools for referrals to clinically appropriate genomic health care services across all health settings.	Long term	AHMAC
ACTION 18: A: Use the National Stocktake of Genetic and Genomic Testing and build links with other data sources (including patient, socio-economic, and health system data) to identify potential inequities in service provision and access. B: Explore opportunities to continue the stocktake on a regular basis and, where appropriate, expand parameters to improve on data collected (including information on infrastructure, testing policies and socio-economic disadvantage) in order to inform future planning and policy development.	Short term	CPC

Implementation of Strategic Priority 5: DATA

Responsible collection, storage, use and management of genomic data

CURRENT GOVERNMENT ACTIVITIES

A number of jurisdictions are investing in developing standards, policies and procedures to support a common infrastructure for the management and use of clinical genomic data (including genotypic and phenotypic data). The next step is for governments to agree on a national approach to sharing health genomics data and arrangements to agree on and embed national health genomics data standards (taking into consideration international approaches).

The key contribution of the Commonwealth is to develop a digital health framework that can capture genomics information in a way that ensures that Australia's digital health foundations support the advancement of genomics. It will be important to ensure that capacity exists to integrate population and health system data with genomic data in order to better develop health policy.

PRIORITY AREAS FOR ACTION

5.1 Establish a national genomic data governance framework that aligns with international frameworks.

- 5.1.1 Explore infrastructure options for national genomic data collection, storage and sharing
- 5.1.2 Strengthen public trust of data systems and mechanisms so that people are empowered to engage with genomic interventions in the health system.

5.2 Promote culturally safe and appropriate genomic and phenotypic data collection and sharing that reflects the ethnic diversity within the Australian population, including for Aboriginal and Torres Strait Islander peoples.

5.3 Develop nationally agreed standards for data collection, safe storage, data sharing, custodianship, analysis, reporting and privacy requirements.

5.4 Promote public awareness of the contribution of all research activities, including those funded through private industry, to advancing the application of genomic knowledge to health care.

5.5 Support sector engagement with international genomic alliances to promote shared access to data for research and global harmonisation of data where appropriate.

IMPLEMENTATION ACTIONS

These actions are to support the collection and analysis of genomic data to drive improvements in health outcomes for all Australians and provide a pathway to truly personalised health care.

NATIONAL ACTION	TIME FRAME FOR COMPLETION	LEAD RESPONSIBILITY
ACTION 19: Develop a national genomic data governance framework that provides for appropriate decision-making for governments and aligns with international frameworks.	Long term	AHMAC
ACTION 20: A: Adopt international best practice standards on cybersecurity and privacy standards for genomic data systems and data sharing across all levels of the health system, including consideration of vulnerable populations. B: Consider the national adoption of appropriate international standards on (but not limited to) phenotypes, disease classification systems, and pathogenic variants.	Long term	AHMAC, Commonwealth
ACTION 21: A: Leverage opportunities for integration of individual genomic information with electronic health records (including, but not limited to, My Health Record) in ways that maintain public trust and improve engagement. B: Explore opportunities to capture and integrate population genomic information to inform health care decisions, research and policies.	Long term—ongoing	Commonwealth, states/territories
ACTION 22: Through consultation and engagement, develop information resources tailored to the general population and vulnerable groups in the community on the implications and benefits of genomic data sharing to build community trust in the delivery of health care and for secondary purposes such as research.	Long term—ongoing	CPC, Commonwealth, states/territories
ACTION 23: Build on existing work to develop a national proof of concept for data sharing across IT systems in different health care and research settings (such as pathology laboratories, hospitals, registries and research institutions).	Long term	Commonwealth

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All information in this publication is current as at May 2018