

Expert Advisory Group on Genomics Australia

Terms of Reference

Context

Genomic health technologies use genomic information about an individual to inform clinical care. They have the potential to reshape clinical practice and change the way we prevent, diagnose, treat and monitor illness.

Already, genomic health technologies are making an impact in the fields of oncology, pharmacology, rare and undiagnosed diseases, and infectious diseases.

Embedding genomic heath technologies in the Australian healthcare system requires a coordinated and strategic approach to ensure that resources are harnessed in an efficient, effective, ethical, and equitable way to deliver tangible health benefits for all Australian patients.

In March 2022 funding was announced for the establishment of a new body to drive the translation of genomic science into improved clinical care –referred to as *Genomics Australia*.

It is anticipated that the new body would:

(a) provide leadership on the coordination of a national approach to integrate genomic health technologies into the health system to improve the lives of Australians.

This may include:

- the development of a national legal and ethical framework to underpin genomics research and clinical practice
- the development of national standards for the collection, storage and use of genomic information
- the national workforce requirements to support this agenda.
- (b) inform the implementation of effective and appropriate measures to improve patient access to clinically supported genomic health technologies in an efficient, ethical, equitable and nationally cohesive way.
- (c) Facilitate the conduct and translation of successful research and trials in the field of genomic medicine into widespread clinical practice.

The Australian Government is committed to collaborating with the research and clinical communities and state and territory governments to accelerate breakthroughs in diagnosis and treatment.

Purpose

The role of the Expert Advisory Group (the Advisory Group) is to advise the Government on the optimal design, role, key priorities and critical partnerships of the new national genomics body to ensure the integration of genomic health technologies as standard elements of healthcare in Australia.



Specifically, the Advisory Group will provide advice to the Commonwealth Government through the Department of Health and Aged Care and the state and territory governments through the Health Technology and Genomics Collaboration (HTGC) on:

- Optimal design, role and purpose of a national genomics body
- Identification of barriers and issues experienced in the current healthcare context which impede the translation of genomic science into improved clinical care
- Identification of key short-term, medium term and long-term priorities to reduce the barriers and drive the translation of genomic research and technologies into standard health care in Australia.

Governance

Term and schedule of meetings

The Advisory Group is time-limited and task oriented. It will be established in July 2023 and is convened until 30 June 2024. The Terms of Reference and membership will be reviewed at the end of this period with the option to extend if required.

It is anticipated the Advisory Group will meet as required by teleconference or video conference, or as otherwise agreed by the membership.

Meeting notes will be taken by the Department of Health and Aged Care as a record of discussion and advice.

Membership

Members of the Advisory Group include researchers, clinicians, industry and consumer representatives on the basis of their expertise or interest in genomic health technologies.

The Advisory Group is co-chaired by Professor Kathryn North AC and a Deputy Secretary or delegate from the Department of Health and Aged Care. Secretariat support is provided by the Department of Health and Aged Care, Genomics and Health Technology Branch.

Responsibilities

All Advisory Group Members are required to:

- possess knowledge and subject expertise on health genomics and its translation to clinical care
- provide advice and expertise related to the establishment of a national genomics body.

Advisory Group members are expected to bring their expertise and background to inform discussions as to the formation of the new genomics body, but not promote/advance personal or professional interests associated with their other engagements and appointments.



Consultation

The Government will separately consult and receive advice from state and territory governments and the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics.

Aboriginal voice and views

The Advisory group will consider the voice and input of Aboriginal and Torres Strait Islander people through the advice of relevant member experts and where required through consultation with external experts, including through the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics.

Confidentiality & conflict of interest

The Advisory Group may, on occasion, be provided with confidential material. Members shall not disclose this material to anyone outside the Advisory Group and shall treat this material with the utmost care and discretion. Members are asked to sign a Deed of Understanding in relation to confidential information and conflict of interest.

The Department of Health and Aged Care will take all reasonable steps to advise members of the status of information and/or documents with regard to their confidentiality.

Conflict of interest is defined as any instance where an Expert Advisory Group member, partner or close family friend has a direct financial or other interest in matters under consideration or proposed matters for consideration by the Advisory Group. Members must disclose to the Department of Health and Aged Care any situation that may give rise to a conflict of interest or a potential conflict of interest and seek the Department's agreement to retain the position giving rise to the conflict of interest. Where a member gains agreement to retain that position, the member must not be involved in any related discussion or decision-making process.

Where a member requests to consult externally about Expert Advisory Group business, this will be discussed on an 'as required' basis with the Co-Chairs.



Appendix A

Co-Chairs	Role
Penny Shakespeare	Co-Chair, member, Commonwealth representative
Prof Kathryn North AC	Co-Chair, member, individual technical
Members	
Mrs Jane Bennett	Member, consumer advocate
Prof Alex Brown	Member, individual technical
Dr Kevin Carpenter	Member, individual technical
Prof Jon Emery	Member, individual technical
Ms Louise Healy	Member, consumer advocate
Prof Oliver Hofmann	Member, individual technical
Prof Dorothy Keefe PSM	Member, individual technical
Mr Robert McBride	Member, individual technical
Prof Julie McGaughran	Member, individual technical
Dr Kym Mina	Member, individual technical
Ms Madeline O'Donoghue	Member, individual technical
Prof Margaret Otlowski	Member, individual technical
Assoc Prof Beverley Rowbotham AO	Member, individual technical
Prof Robyn Ward AM	Member, individual technical
Ms Trinity Mahede	Member, state and territory representative