



# Queensland Genomics Health Alliance

## Community Group

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### Terms of Reference

## Document Purpose and Audience

The purpose of the Queensland Genomics Community Group Terms of Reference is:

- Serve as the charter for the Queensland Genomics Community Group.
- To provide establishment information about the Queensland Genomics Community Group including its vision, purpose, role, principles, membership, terms of office, member responsibilities, meeting and operational procedures.
- Be read in combination with the Queensland Genomics Community Group Orientation Pack.

The primary audiences for the Queensland Genomics Community Group Terms of Reference are:

- The Queensland Genomics Community Group membership
- The Queensland Genomics Operational Program Committee (OPC)
- Queensland Genomics funded projects
- Queensland Health

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The University of Queensland - The Queensland Genomics Health Alliance is administered by the University of Queensland. [www.uq.edu.au](http://www.uq.edu.au)

The Queensland Genomics Health Alliance – members of the alliance that have contributed to workshops guiding the business mode, goals and objectives for the Queensland Genomics and its ongoing works.

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# 1. About Queensland Genomics

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## Overview

The integration of genomics into everyday healthcare has the capacity to transform the delivery of health services globally with faster diagnosis, new treatments, and more cost-effective service delivery.

Queensland Genomics aims to bring genomics into everyday healthcare in Queensland and is a collaboration involving Queensland-based universities and research organisations, Queensland hospitals and health services, private health providers, and associated health organisations throughout the State.

Queensland Genomics focuses on a number of Capability Building Workstreams and Clinical Demonstration Projects to support the use of genomics in the healthcare setting in Queensland.

### Capability Building Workstreams

The Capability Building Workstreams aim to establish infrastructure and capacity to support the use of genomics within Queensland's health services. The Five Capability Building Workstreams are:

- Genomic Information Management
- Genomic Testing Innovation
- Genomic Workforce Development
- Ethics, Legal and Social Implications of Genomics
- Evaluation of Clinical Genomics

### Clinical Demonstration Projects

The central objective of the Clinical Demonstration Projects is to evaluate the use of genomic sequencing in the diagnosis and management of patients in specific disease areas. The four current Clinical Demonstration Projects are:

- Melanoma
- Lung Cancer
- Hospital-acquired Infections
- Maturity-Onset Diabetes of the Young (MODY)

### Queensland Genomics Objectives

With a longer-term mission to improve the health of Queenslanders, Queensland Genomics' vision will be achieved through its core objectives:

1. Workforce able to incorporate genomics into healthcare;
2. An evidence base for clinical genomics;
3. Timely and cost-effective diagnostic workflows;
4. Genomic sequence results are used for the benefit of patients;
5. Public awareness and understanding;
6. A system for the management of clinical genomic data;
7. Accelerated translation of research; and
8. A positive contribution, nationally and internationally.

## 2. Queensland Genomics Community Group Terms of Reference

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### Vision

The Queensland Genomics Health Alliance Community Group is an active collaborator within the health system working with researchers, clinicians and communities to facilitate equitable and accessible person-centred care for all Queenslanders.

### Objectives

- To collaborate with Queensland Genomics Health Alliance and support its vision and mission
- To serve as an active conduit to consult, promote, and engage the people of Queensland in the work of Queensland Genomics Health Alliance and its partners
- To support the development of a health system that delivers the earliest possible diagnosis, appropriate intervention and follow up, and responds to patient needs in a flexible and nuanced person-centered way
- To advise Queensland Genomics Health Alliance projects on better ways to link and communicate with patients and their families, helping to ensure a patient and delivery focus

### Themes of our work

#### Collaboration

The Queensland Genomics Community Group supports and drives collaboration and communication between community, consumers, advocacy groups, clinicians, health systems, researchers, locally, nationally and internationally, and others, with the aim of informing the implementation of genomics into healthcare.

#### Equity and Access

The Queensland Genomics Community Group supports equity of access to genomic medicine regardless of location, education, language, socio economic status, or health literacy. The Queensland Genomics Community Group works to improve clarity of treatment pathways, diagnostic tools and genomic medicine.

#### Education

The Queensland Genomics Community Group builds education on different perspectives of genomic medicine within communities of health consumers, carers, clinicians, researchers, health administrators, advocates.

#### Advocacy

The Queensland Genomics Community Group is a respected group who advocates for the community with government, NGOs, private sector to enable patient-centred personalised medicine now and into the future.

#### Foundation and prioritisation

The Queensland Genomics Community Group recognises its role as laying down the tracks and setting the direction to build long term changes in the health system for the introduction of genomics. We work to help prioritise activities, balancing the desire to make a difference not only today, but also in the longer term.

#### Real world context

The Queensland Genomics Community Group helps to frame actions and decisions within the real-world context experienced by consumers and community. We work to improve the understanding of researchers, clinicians, and decision makers in the health system about the real-world impacts of decisions, and the current experiences and challenges of consumers, families and communities.

## Areas of Action: our work with key stakeholders

### Queensland Genomics

- Collaborate with Queensland Genomics and support its vision and objectives
- Serve as a conduit to consult and promote, and to engage the people of Queensland in the work of Queensland Genomics and its partners
- Focus on consumer issues – in Queensland Genomics projects and the broader program
- Ensure activities of Queensland Genomics are relevant and beneficial to patients and communities across Queensland

### Community

- To be a voice for all Queenslanders
- Engage with the community – educate so that utility and limitations of genomics is understood, and community concerns addressed. Use positive stories regarding genomics to build awareness and understanding.
- Increase awareness about the lives of people with genetic conditions. Help to bridge knowledge gaps.
- Ensure the views of different sectors of the Queensland Genomics community are considered in implementing genomics

### Clinicians

- Enable clinical understanding in ‘real world’ context
- Support better education of clinicians in medical training, and ongoing professional development

### Health System

- Lay the foundations for health system to implement genomic medicine, ensuring diverse community voices, needs and issues are understood and responded to
- Support development of patient-centred policy, design and implementation
- Provide community input into patient-facing resources
- Provide a patient/community voice to enrich the application of genomics for patient benefit
- Create change and make genomics more accessible
- Help to identify future important areas in genomics where Queensland can have the greatest impact
- Help prioritise activities and balance what makes a difference today with what makes a difference in the longer term
- Provide a reality check about the consumer experience and the challenges of getting on, or being on a treatment pathway and the impacts that this has on the consumer and their family, friends and community

### Research

- Advise research projects on better ways to link and communicate with patients
- Support a community voice in development of genomics research and policy
- Ensure research focus remains on improved healthcare and patient needs

## Membership

Queensland Genomics Community Group members will contribute specialist knowledge and expertise by providing consumer, carer, clinician, health researcher and community perspectives. They will contribute as informed individuals, representing all health consumers and the broader community not as a representative of any one organisation, disease area, or individual.

In seeking nominations, the Executive Director will liaise with Queensland Health, HHS's, Queensland Genomics projects, Health Consumers Queensland, and relevant community organisations.

The Queensland Genomics Community Group will have a minimum of five community members and maximum of eight members. The Group as a whole should directly or indirectly bring diversity in terms of age, gender, geography, ethnic background, disability, and medical conditions.

The Chair of the Queensland Genomics Community Group will be nominated by the Executive Director. Members will be nominated by the Executive Director and approved by the Chair.

A member of the Queensland Genomics Ethics, Legal and Social Implications of Genomics (ELSI) will attend all meetings in an ex-officio capacity due to that project's objectives relating to community engagement.

A representative from Queensland's Statewide genetic health service Genetic Health Queensland will be invited to attend all meetings in an ex-officio capacity.

The Queensland Genomics Executive Director will attend all meetings in an ex-officio capacity.

The Queensland Genomics Communications and Engagement Manager will attend all meetings in an ex-officio capacity.

Other members of the Queensland Genomics Operational Program Committee will attend Queensland Genomics Community Group meetings as required, to support discussion regarding specific projects.

## Terms of Office

The term of service of members is 12 months and members may re-nominate. Group members will cease to be a member if they:

- Resign from the Group; or
- Do not attend at least half of all scheduled meetings in a calendar year.

If a Group member ceases to be a member, a replacement will be recruited to fill that vacancy.

## Proxies

Ex-Officio members may send a proxy if they are unable to attend a meeting.

There will be no other proxies for Queensland Genomics Community Group meetings.

## Meetings

Formal meetings will be quarterly and may be held face-to face, by telephone, videoconference, or other electronic means.

Members of the Queensland Genomics Community Group may be required to deal with ad hoc matters outside of formal meetings. For ad hoc matters which are dealt with outside of the regular quarterly meeting schedule it will be the decision of the Executive Director in consultation with the Chair, who from the Group deals with ad hoc matters. Any ad hoc matters will be noted within the minutes of formal meetings. Should there be concern over how these matters are being dealt with, members should make these concerns known directly to the Executive Director.

The frequency of meetings can be reviewed at any time and additional “out of session” meetings or papers can be called to meet the needs of the Queensland Genomics Program.

## Meeting Procedure

The Chair of the Queensland Genomics Community Group chairs all meetings of the Queensland Genomics Community Group, except if the Chair has a conflict of interest or is unavailable, in which case the Chair will delegate an interim Chair. The Queensland Genomics Community Group regulates its own meeting procedures.

## Responsibilities of the Chair

The Chair's duties and responsibilities include, but are not limited to, the following:

- In consultation with the Queensland Genomics Executive Director, and Queensland Genomics Communications and Engagement Manager schedule dates, times and location for meetings;
- In consultation with the Queensland Genomics Communications and Engagement Manager establish an agenda for each meeting;
- Represent the Queensland Genomics Community Group in other forums at the request of the Queensland Genomics Executive Director;
- Attend and facilitate meetings and discussions between members;
- Provide leadership and ensure that meetings are held in accordance with the Queensland Genomics Community Group Principles of Engagement (see page 5);
- Review and approve meeting minutes within 48 hours of receipt.

## Responsibilities of Members

Members' duties and responsibilities include, but are not limited to, the following:

- Act in accordance with the Queensland Genomics Community Group Principles of Engagement (see page 5);
- Read relevant background ahead of meetings and ensure that discussion on agenda items is on topic, productive and professional;
- Attend and contribute to meetings;
- Represent and advocate for the views of their communities;
- Share learnings and outcomes of discussions with the communities they represent.



## Quorum

A quorum for the Group meeting is defined as the presence of the Chair (or Chair's delegate) and a majority of members (excluding ex-officio members). Where attention is drawn to a loss of quorum, the meeting may be adjourned until such time as the Chair may determine. A quorum must be present for the Group to make recommendations.

## Governance

Recommendations of the Group members may be made at a duly called and constituted meeting; or, by a recommendation in writing to all members of the Group. Group members' recommendations will be provided to the Executive Director, Project Leads, or Operational Program Committee for consideration.

The Queensland Genomics Executive Director may seek opinions and views external to the membership. These views will be shared with members to enrich the quality of conversation.

Minutes are to be prepared after each Group meeting. Any recommendations made by the Group will be confirmed in the Minutes. A copy of the Minutes, once they have been reviewed by the Chair, will be circulated to all members as a draft, and included in the agenda papers for the subsequent Group meeting.

## Evaluation and Review

To ensure that this Group is fulfilling its duties, it will:

- Be initially evaluated as part of the planned Queensland Genomics Governance Review (2018);
- Run a Queensland Genomics Community Group Impact register to track activities and outcomes achieved;
- Report into the quarterly Queensland Genomics Governance Meetings as required;
- Undertake an annual self-assessment of its performance against its Terms of Reference and provide that information to the Executive Director via the Chair; and
- Provide any information the Executive Director may request to facilitate its review of Group's performance.

## Community Group Administrative Support

The Queensland Genomics Community Group will receive administrative, logistical and operational support from Queensland Genomics, to coordinate communication, meetings, and to facilitate effective and efficient function of the Queensland Genomics Community Group.

## Schedule of Meetings

The Queensland Genomics Community Group will meet on a quarterly basis, and may hold additional meetings when required. Quarterly meetings will be scheduled prior to Operational Program Committee meetings, so the Queensland Genomics Community Group's deliberations can be passed onto the Operational Program Committee meeting.

## Notice of Meetings

Notice of any meeting of the Group shall be given in writing no fewer than ten working days before the day of the meeting.

## Distribution of Information

Written information is distributed to members of the Group by electronic means. Information is deemed delivered 24 hours after dispatch of the information.

## Agenda and Papers

The Communications and Engagement Manager is responsible for drafting the agenda and preparing papers for the Group, in consultation with the Chair. The Communications and Engagement Manager will request agenda items from members at least two weeks prior to the next meeting. The Communications and Engagement Manager provides the agenda and coordinates distribution of documents in liaison with the QHGA Community Group Chair. Agenda and documents are provided to members no fewer than five working days prior to any Group meeting. In consultation with the Executive Director and Communications and Engagement Manager, the Chair may decide not to list an item on the formal agenda, however, members may raise an item under 'Other Business' if necessary and time permits.

## Confidentiality

As a general rule, members of the Group hold confidential all information provided to them in their role as a Group member. At times, members of the group may need to use information provided to them in their role as a Group member to support advocacy and engagement activities and this must be done in accordance with agreed communications protocols.

## Conflict of Interest

Group members are required to bring to the attention of the Chair any conflict of interest or potential conflict they may have with any item on the Group's agenda.

If a Group member is deemed to have a real or perceived conflict of interest in a matter that is being considered at a meeting, he/she may be excused from the Group's discussions and deliberations on that issue, at the discretion of the Chair.

Conflicts or potential conflicts of interest will be recorded in a register which will be a standing agenda item.

## Honoraria

An honorarium is granted to help support the costs of the Group's community members. Where a member is an investigator on a Queensland Genomics project, a Queensland Health employee, or a paid employee of a consumer, patient, carer or health peak body an honorarium will not be paid.