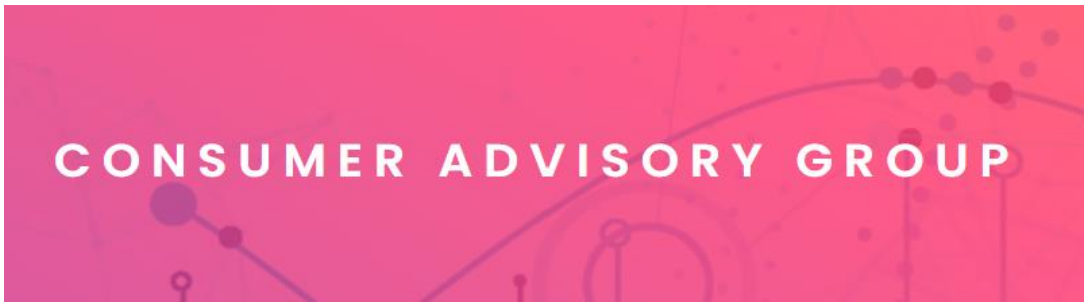


Terms of Reference

Making personalised healthcare accessible to all Australians by harnessing the collective skills and expertise of industry to accelerate the adoption of genomics

September 2025

Contents

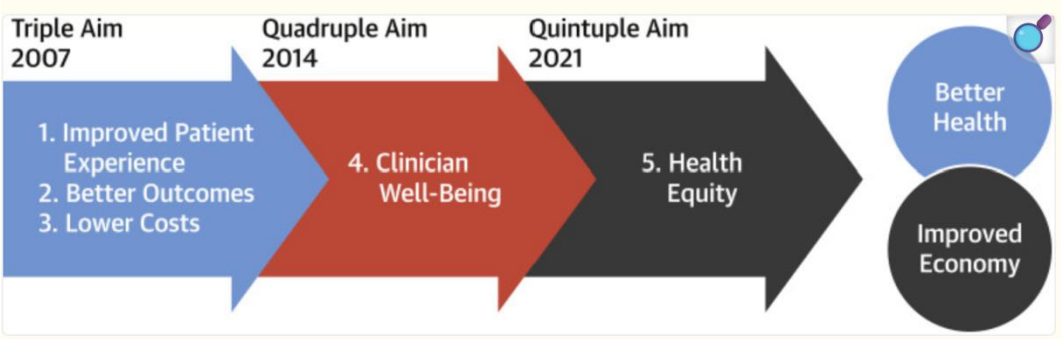
Document Control

Version	Author	Date
V0.1	K Campbell	19 February 2024
V0.2	K Campbell – updated for Board feedback	5 March 2024
V1.0	K Campbell, feedback from Committee Chair and Approval by Board	11 March 2024
V2.0	E Evans – updated to include Honorarium	31 July 2025
V3.0	L.Trueman - updated to include Charter of Expectations	25 September 2025

Background

InGeNA Ltd is the industry body representing organisations working in the genomics sector, with a goal to provide a single voice on behalf of industry ensuring that industry is consulted, heard and included in discussions.

Industry is in a unique position to bring insights and contribute to collaborations that others working in the sector cannot. InGeNA is committed to the Quintuple Aim of Healthcare. Three of the five aims, being improved patient experience, better outcomes and health equity are directly related to consumers.



Source [The Evolution of the Quintuple Aim - PMC (nih.gov)]

For InGeNA to be effective, strong stakeholder engagement and communication is essential. It must be regular, multi-modal and targeted to a range of audiences. Part of this is engagement is with consumers to ensure that our interactions with them are carried out in the most constructive ways, are appropriately focussed, and that our policy development and advocacy work reflects the needs of consumers. To that end, InGeNA has established a Consumer Advisory Group (CAG).

Definition of Consumers

Australia's National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care ("the Commission") in collaboration with the Australian Government, state and territories, the private sector, clinical experts, patients and carers. **Standard Number 2 is Partnering with Consumers** see link Source*: The NSQHS Standards | Australian Commission on Safety and Quality in Health Care*

The Commission defines a consumer as a person who has used, or may potentially use health services, or who is a carer for a patient using health services. A healthcare consumer may also act as a consumer representative, to provide a consumer perspective, contribute consumer experiences, advocate for the interests of current and potential health service users, and take part in decision-making processes.

InGeNA acknowledges that NDIS, Aged Care and Mental Health have similar standards however has decided to adopt the ACSQH one.

In InGeNA's case this means a person who has had an experience of the use of genomics in their health journey or may do so in the future.

Purpose of Consumer Advisory Group

The purpose of the Consumer Advisory Group (CAG) is to provide an independent voice to InGeNA that promotes genomics and the advancement of precision medicine that is respectful and responsive to the preferences, needs and values of consumers and partners; and advise the InGeNA Board and members in areas of strategy, advocacy, education and communication, and policy development. The CAG will represent a cross-section of consumers and consumer groups who can benefit from genomics

Strategic Priorities and Plans

The CAG will assist InGeNA in the development of its strategic plans and provide input into the priorities in the operationalisation of strategic plans.

Education and Communication

CAG members will bring perspectives from their networks and cohorts to discussions with InGeNA. They will consult with broader groups if relevant and feed information or requests for input from InGeNA back into their networks when requested. They will help ensure that the InGeNA Board and Members are cognisant of consumer needs and understand how to best engage with consumers.

CAG members will also promote the work of InGeNA when such opportunities arise.

Policy

As part of InGeNA's policy development process, the CAG will be consulted to ensure that consumer perspectives and priorities are considered and addressed as appropriate.

Decision Making and Relationships

The CAG is an advisory body to the InGeNA CEO and has no decision-making powers. The CAG is a committee within the InGeNA structure. From time to time the InGeNA Board may request a report or presentation from the CAG.

The CAG will work collaboratively with and be consulted by InGeNA staff, members, volunteers, consultants and partners as required to provide input to various initiatives.

Membership

Members of the CAG will bring a cross- section of attributes and experience in the following areas:

- cultural including First Nations and CALD
- geographical spread, across Australia and metro/regional
- age groups
- gender
- lived and living experience across a range of disease groups, of different types of prediction, prevention, diagnostics, treatment and management, and at different stages of the health/wellbeing journey
- professional experience and/or qualifications in genomics and/or healthcare

Members will be expected to demonstrate a passion for genomics, an understanding of the role of genomics in healthcare, and show a willingness to learn about broader health system, the flow of genomic information, the funding mechanisms, and the full patient/consumer journey. They should also show an interest in developments in the genomics field.

The CAG will consist of up to ten members plus a Chair who will be appointed by the InGeNA Board. The members will be appointed by InGeNA in consultation with the Chair of the CAG. The InGeNA CEO will be an ex-officio member of the CAG with a team member to support secretariat. InGeNA Board Members and/or general members will be invited to attend when relevant.

Benefits for Members

As members of the CAG, participants will have the opportunity to:

- connect with and influence industry policy positions and how industry engages with consumers
- connect with peers and learn about issues and challenges different consumers and consumer groups face
- explore issues collaboratively, and
- potentially engage with members or partners on research projects or in consumer consultation activities

In addition, members may have the opportunity to attend InGeNA Member only events at no cost. They may also be invited to attend InGeNA in-person public events at either a highly subsidised price or at no cost. Where agreed and approved in advance expenses related to participation in the CAG will be reimbursed.

Honorarium and Reimbursement Policy

In line with InGeNA's commitment to fair consumer representation and sector standards for remuneration, the Board has agreed to pay an honorarium to Consumer Advisory Group (CAG) members based on their participation in the regular CAG meetings. This support acknowledges the value of lived experience and time contributed.

The honorarium arrangements will be reviewed and confirmed annually as part of InGeNA's budgeting process.

InGeNA does not provide taxation advice. Members are responsible for their own taxation and financial decisions. In general terms, the Australian Tax Office does not consider an honorarium as taxable income.

Meetings

Meetings will be held between four and six times per year. All meetings will be virtual. Meetings will be booked annually in advance after consultation with members. Additional ad-hoc meetings may be called to discuss a particular topic, particularly if there is an externally imposed deadline.

Expectations of Members

Attendance

Members are expected to attend all meetings. Should a member fail to attend three planned meetings in a row, they will be requested to resign their CAG membership unless there are extenuating circumstances, such as health issues. Should such circumstances exist, each case will be considered by the CAG Chair and the InGeNA CEO on an individual basis.

Potential Conflicts of Interest

A register of interests will be maintained. CAG members are required to ensure that any new interests or potential conflicts are declared to the CAG Chair and InGeNA CEO.

CAG members will not use their position with InGeNA, connections gained via InGeNA, or attendance at any InGeNA event to promote the work of any other organisation or their personal/professional/family interests. Nor should they use their position to gain work for any financial gain – personally or for a related business. Should they be found to have breached this requirement they will be required to resign from the CAG immediately. Should this happen inadvertently, such as applying for an advertised employment opportunity or tendered consulting work, or being approached directly for such, this should immediately be raised with the CAG Chair and the InGeNA CEO to assess the best way to address the situation.

Charter of Expectations

CAG CULTURE CHARTER

This culture charter outlines the values and engagement expectations including core principles, behaviours, and standards for our CAG. They serve as a guide for decision-making, actions, and interactions, promoting a shared understanding of what is considered acceptable and desirable.

- We will work together in an inclusive, supportive and respectful environment towards agreed goals and objectives.
- We acknowledge shared responsibility to engage and participate as a remunerated member of the InGeNA CAG.
- We resolve to refrain from aggressive or dominating behaviours.
- We work on the assumption we are all committed to the CAG objectives and outcomes, so if someone “drops the ball” we will seek to support rather than blame them.
- We recognise that we act in partnership with the broader InGeNA membership

Strategies for realizing these ideals include:

- Team meetings will begin and end with a quick check in to see how we are all doing to raise awareness that we all have pressures beyond the CAG and that these can impact how we "show up" from day to day.
- Any major activity will have a plan for delivery. This will not only help to ensure work is shared but also that there is a backup if needed
- . We engage actively with the InGeNA membership to ensure a mutually beneficial relationship
- We will celebrate our achievements when we are done!

Meeting Values

- We are punctual
- We attend meetings unless there are unavoidable conflicts or events and forward any apology at least 3 business days prior where possible.
- We actively participate in meetings
- We come to meetings prepared where appropriate
- We accept accountability for any action items assigned at meetings

Term of Appointment

A member is appointed to the CAG for a three-year term, with an option for a one term renewal. When the first appointments are made, only half the Committee will be offered an option to renew at the end of their first term. This is to ensure that there is turnover of membership and that InGeNA does not face a complete turnover of CAG membership after six years.

Acceptance of and Agreement to Terms of Reference

_____ CAG Member Name

_____ Signature

_____ Date