#

Participant Panel Terms of Reference 2024

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Date: 05/02/2024

Contents

[1. Mission 3](#_Toc163207468)

[1.1 Remit 4](#_Toc163207469)

[1.2 Limits to Panel remit 4](#_Toc163207470)

[2. Panel Activities 5](#_Toc163207471)

[2.1 Quarterly Panel meetings 5](#_Toc163207472)

[2.2 Additional Panel meetings 5](#_Toc163207473)

[2.3 Panel dashboard 5](#_Toc163207474)

[2.4 Representing research participants at Genomics England 6](#_Toc163207475)

[2.5 Additional activities 6](#_Toc163207476)

[2.6 Links with NHS Genomic Medicine Service 7](#_Toc163207477)

[2.7 Links with Genomics England staff 7](#_Toc163207478)

[2.8 Communicating with people whose data is held by Genomics England 7](#_Toc163207479)

[3. Panel membership arrangements 8](#_Toc163207480)

[3.1 Makeup of the Panel 8](#_Toc163207481)

[3.2 Appointment of new Panel members 8](#_Toc163207482)

[3.3 Time commitment 8](#_Toc163207483)

[3.4 Stepping down from the Panel 8](#_Toc163207484)

[3.5 Panel Associates 9](#_Toc163207485)

[3.6 Expenses and honoraria 9](#_Toc163207486)

[3.7 Chair and Vice Chair roles 9](#_Toc163207487)

[4. Training 10](#_Toc163207488)

[5. Conduct 11](#_Toc163207489)

[5.1 Nolan Principles of Public Life 11](#_Toc163207490)

[5.2 Engagement with the media 11](#_Toc163207491)

[5.3 Social media use 12](#_Toc163207492)

[5.4 Complaints 12](#_Toc163207493)

[6. Review 12](#_Toc163207494)

1. Mission

The Participant Panel (‘the Panel’) is a voluntary advisory group,  representing the interests of the thousands of people whose data is held by Genomics England in the National Genomics Research Library (‘NGRL’). This includes the participants in the 100,000 Genomes Project, patients in the COVID-19 GenOMICC study, cohorts from the Diverse Data initiative, and NHS Genomic Medicine Service patients who choose to participate in ongoing research, including the Generation Study. The NGRL will include other cohorts in the future.

Panel members bring direct lived experience as patients or carers of people with rare conditions, cancer or COVID-19, or as parents of newborn babies who have chosen to join the Generation Study. The Panel works with Genomics England to ensure that the diverse voices of participants, patients and their families are heard and understood at all levels of the organisation. The Panel demonstrates its impact by strategically influencing the decisions made within Genomics England about who uses participants’ sequenced genomes and associated health data, and what it does with this data; and by helping Genomics England to engage with patients, participants, their families and the wider public in mutually beneficial ways.

The Chair of the Panel reports directly to the Chair of the Genomics England Board.

1.1 Remit

Participant Panel members are not employees of Genomics England but may be reimbursed for expenses and time spent on Genomics England business.

The remit of the Participant Panel is to:

* Work collaboratively with Genomics England, its Board and other relevant healthcare bodies, helping to improve links between patients/participants and health researchers (from academia and industry) and clinicians;
* Keep holding Genomics England to account for what it does with all the research participant data it holds, seeking to ensure that data is being held safely and used for the public good;
* Continue to pursue results for the 100,000 Genomes Project participants and their families in perpetuity, including Additional Findings, and make sure that all the NGRL cohorts continue to benefit from advances in technology;
* Provide advice to Genomics England on any aspect of its activities, upon request, based on Panel members’ lived experience as research participants, patients and carers; and
* Champion, and facilitate where possible, genomics-based health research using the NGRL that embodies the principles of coproduction, where project participants/patients and their families can share the benefit of their lived experience, if they wish.

1.2 Limits to Panel remit

The Panel has a unique and specific role within the ‘genomics ecosystem’. Collectively the Panel advises Genomics England, in relation to decisions that are made about the data in the NGRL, and about the people whose data are in the NGRL.

The Panel has an interest in the recruitment of NHS patients into the NGRL for research purposes, but it has no influence over decisions made in the NHS about patient care.

The Panel has an interest in how research findings are relayed back the NHS, and has been advising the Generation Study about returning findings to its participants.

The Panel has no influence on NHS clinical practice, although individual Panel members’ lived experiences of NHS care can and should inform the Panel’s advice to Genomics England where applicable.

2. Panel Activities

2.1 Quarterly Panel meetings

The full Participant Panel meets 4 times a year, at least some of these in person if possible, but with an online option for anyone who would prefer not or is unable to travel.

Meeting dates will be set as far in advance as possible, ideally on an annual basis. These will be designed to fall on different days of the week across the year.

Meetings last for a full day (e.g. 10am-4.30pm) and are generally followed by an optional opportunity for relaxed discussions to continue.

All Panel members are encouraged to submit suggestions for sessions at Panel meetings; a draft agenda will be circulated around 6 weeks in advance of a Panel meeting for comment.

Speakers will be asked to provide a summary of their presentation 1 week ahead of time, so that the Panel can read and digest in advance. This information should be provided in a format that is accessible to each Panel member. The Panel Secretariat will be asked to provide any technical support that may be necessary to achieve this. Speakers who fail to provide the requested materials in good time may find their slot is deferred until the next meeting, at the Chair’s discretion.

Speakers will be asked to allow for at least 50% of their allotted time as Q&A, to ensure a full and detailed discussion with and among the Panel members OR will be expected to facilitate a separate follow-up call with Panel members after the meeting to discuss in more detail.

Summary meeting Minutes will be shared with the Panel and the Genomics England Leadership Team within 1 month of the meeting and will include a list of actions for follow-up at the next meeting.

Meetings will be supported by the Panel Secretariat provided by Genomics England.

2.2 Additional Panel meetings

Additional Panel meetings may be held between full meetings, by request of the Panel or by Genomics England.

These meetings typically last up to 1 hour and enable the Panel to discuss a specific topic in more depth, generally with a relevant member or members of Genomics England staff present. The Panel leadership also attend a monthly meeting with the Communications and Engagement team.

Panel members are encouraged to attend but these are not compulsory.

2.3 Panel dashboard

One of the Panel’s main roles is to hold Genomics England to account for what it does with all the research participant data it holds, seeking to ensure that data is being held safely and used for the public good.

To support this role, a ‘dashboard’ of key monitoring information agreed with the Panel will be collated and circulated by Genomics England ahead of each Panel meeting, regarding the progress of its major programmes.

This dashboard is presented as a standing agenda item at each quarterly Panel meeting by the Chief Scientist, Chief Medical Officer, or their nominated deputy.

The dashboard includes the following information for the previous quarter (and change from the quarter prior to that):

* Progress by the Diagnostic Discovery team: the number and nature of tentative new findings reported to the GMS for verification;
* Recruitment breakdown: numbers of participants in the component studies within the NGRL wherever possible, this should be broken down by health condition / subject area, ethnicity, GMSA region, etc; and
* Research Network progress: number of researchers actively working in the Research Environment (as a sub-set of the total number with access rights); number of papers published by each Research Network domain; link to lay summaries of these (where available).

2.4 Representing research participants at Genomics England

Panel members represent the research participant community by sitting on the following independent advisory committees that report to the Genomics England Board:

* Ethics Advisory Committee (EAC),
* Access Review Committee (ARC),
* Research Network (RN) Committee.

Membership of these committees/other bodies is governed by Genomics England. Individuals representing the Panel in these other fora will be subject to their respective Terms of Reference.

Periodically, Genomics England may ask the Panel to nominate new representatives for these committees. At such time, the Panel Chair will invite volunteers from the whole Panel to submit a short written expression of interest, outlining their relevant skills and experience. The Panel Chair will consider these and nominate one volunteer to fill the relevant Panel representative vacancy (or vacancies, where applicable). The Chair of the relevant committee will accept or decline the nomination(s). If a nomination is declined, the Panel Chair will seek feedback and, if necessary, propose an alternative nominee.

In order to be appointable as a Panel representative to one of these committees, an individual must be a Participant Panel member. Individuals representing the Panel on these committees may remain in post until their term on those committees expires, or their Panel membership expires, whichever is the sooner.  Each Panel member may only represent the Panel on one committee at a time.

The Panel representatives will monitor the effectiveness of these committees, from participant community perspectives, reporting any concerns back to the Participant Panel and its Chair. If necessary, the Panel Chair may escalate to the Genomics England Board for consideration.

Genomics England will brief the Participant Panel on new collaborations and partnerships in new emerging areas where these may impact NGRL data.

2.5 Additional activities

The Panel may receive one-off requests for advice from Genomics England and other trusted public bodies in the fields of health care and genomics-based data research. This may include setting up a ‘task and finish’ group to deliver that advice.

For longer term initiatives, Panel members may establish ‘working groups’ (for example, on the Generation Study, or Patient/Participant Communications and Engagement) to offer targeted input on these subjects to Genomics England. This may entail attending extra online meetings and developing written materials where Genomics England and Panel members agree this would be useful.

The ‘working groups’ will have a nominated participant panel member to coordinate the work and meetings with Genomics England staff and fellow panel members.

Each ‘working group’ will have outline Terms of Reference to ensure clarity around their remit and intended output/impact.

These activities will be supported by the Panel Secretariat or another Communications and Engagement team member where necessary.

2.6 Links with NHS Genomic Medicine Service

The Panel will maintain a strong relationship with the national ‘People and Communities Forum’ that is run by the NHS Genomic Medicine Service and brings patient representatives together to oversee the work of the GMS.

The Participant Panel Chair (or nominated deputy) will sit on the Forum, and the Forum Chair may be invited to attend Participant Panel meetings as an observer.

There may also be scope for joint (training) events with Forum members in due course.

Some Panel members may also have regional roles in the NHS Genomic Medicine Service Alliances across England. These roles are not functionally linked to the Participant Panel, but may offer opportunities for cross-fertilisation of ideas between the different bodies.

2.7 Links with Genomics England staff

The Panel’s main connection is with the Communications and Engagement team, who may facilitate onward conversations with colleagues where appropriate.

If Panel members have queries and want to speak to specific members of the Genomics England staff, they should do this through the Communications and Engagement team and/or Panel Chair or a Vice Chair. This enables the Panel Secretariat to have a full picture of Panel member activities across the company.

If Genomics England staff wish to approach Participant Panel members, the Communications and Engagement team and/or Panel Chair should be notified and will advise on the best approach forward.

The Panel will work with the People Team to ensure that participant community interests are represented in the onboarding programme for new Genomics England employees. This may include enabling new staff to attend a Panel meeting, providing explanatory materials in onboarding packs, and facilitating introductory meetings between new employees and Panel members.

From time to time, the Panel may be invited to participate in recruitment exercises for senior posts at Genomics England (or the leadership of its independent advisory committees, including the ARC, EAC and RN Committee). Panel members have an advisory role in such exercises and their input is taken into account alongside other key stakeholders.

2.8 Communicating with people whose data is held by Genomics England

The Panel has a ‘front door’ on the Genomics England website, which enables research participants (and the wider public) to:

* Find out what the Panel’s remit is, who sits on the Panel and why, the different roles members have (ARC, EAC, RN Committee, etc), and what outputs/impacts we can demonstrate;
* Submit questions and/or comments to the Panel directly;
* Hear about any vacancies on the Panel; and
* Find links to relevant Genomics England project updates/research activity that might be of interest to them (including contact details for the research lead).

The Panel Secretariat and wider Communications and Engagement team will provide the necessary technical support. The Panel web page will be reviewed periodically to ensure it remains up to date.

3. Panel membership arrangements

3.1 Makeup of the Panel

The membership of the Participant Panel will evolve to include representatives from all the communities who give consent for their samples to be added to the NGRL held by Genomics England. All Panel members will:

* Have lived experience of consenting to share their own whole genome and associated health data in the NGRL, or those of someone they care for;
* Be appointed on a three-year term, with the possibility of one further term extension by mutual agreement with the Engagement and Public Partnerships Director and Panel Chair; and
* Continue to be drawn from as wide a demographic and geographic area as possible, including their home nations where applicable (wherever Genomics England participants come from).

3.2 Appointment of new Panel members

New members will be appointed following a successful interview with Genomics England’s Engagement and Public Partnerships Director and the Panel Chair.

3.3 Time commitment

As representatives of much larger communities of NGRL participants, Panel members have a responsibility to spend sufficient time on their role to ensure their contribution is impactful. Genomics England anticipates this to be in the region of 8 full days per year, including all 4 full Panel meetings if possible.

Participants often have to juggle their own or their family’s health issues and work commitments, and these naturally take priority. Temporary absences can be agreed with the Panel Chair, should a member be unable to engage with the Panel due to parental leave or sickness, for example. However, if a Panel member (i) does not attend 3 quarterly Panel meetings in a row, (ii) is unable to contribute anything between meetings, and (iii) has not informed the Panel Chair of any reason to explain their lack of engagement with the Panel, then they will be thanked for their time and asked to leave.

3.4 Stepping down from the Panel

Panel members are appointed on a 3-year term, with scope for one further extension by mutual agreement with the Engagement and Public Partnerships Director and the Panel Chair.

For the 2023 Panel member cohort and beyond, the second term is anticipated to be no longer than 3 years. For Panel members recruited before 2023, the second term may be longer than this, to ensure a gradual evolution of Panel membership.

Members wishing to stand down before the end of their agreed term may do so at any time, by notifying the Chair and the Panel Secretariat of their decision in writing.

3.5 Panel Associates

Panel members stepping down after at least one year’s service are eligible to become ‘Panel Associates’. Associates will be kept informed about the ongoing work of Genomics England by the Participant Panel, and may be invited by the Chair to contribute to initiatives where their experience as past Panel members or as a representative of a specific community/cohort of participants is of particular relevance. The Panel will update Associates on issues of interest in Genomics England’s activities. An appointed Panel member will be responsible for updating and managing the Associates’ mailing list, acting as the link for any Associate to raise any questions with the Panel or with Genomics England. Only the Participant Panel will receive secretariat services from Genomics England.

3.6 Expenses and honoraria

Panel members may claim expenses and activity payment honoraria in relation to activities that are requested by Genomics England or directly relate to fulfilling the Panel’s stated roles. Expenses policy will keep pace with best practice for public contributors in the health sector.

If a Panel member is unsure whether an activity payment is claimable, they should contact the Head of Engagement / Panel Secretariat for advice before committing to undertake the activity.

Genomics England endeavours to support Panel members who need to arrange care for a family member, in order to participate in Panel activities. Panel members should notify the Panel Secretariat of the approximate cost of this before the expenditure is incurred if planning to seek reimbursement.

All expenses claims must be accompanied by documentary evidence of expenditure (e.g. travel tickets, tax receipts, etc).

Bank statements do not qualify as receipts (except in exceptional circumstances where tax receipts cannot be obtained). If seeking to make an ‘exceptional circumstances' claim, Panel members must discuss with the Panel Secretariat in advance of incurring the expense.

3.7 Chair and Vice Chair roles

Recruitment of the Chair and Vice-Chairs will be led by the Director of External Affairs and a nominated Board member at Genomics England. The job descriptions will be co-designed with the Participant Panel with a selection of Panel member volunteers involved in the recruitment process. The final stage of the recruitment phase will be an interview with the Director of External Affairs.

The Chair of the Panel will be confirmed by the Genomics England Board. They must be eligible to be a Panel member at the time of application. Their initial term will be 3 years from the date of appointment, with the possibility of one further term of 3 years following a successful ‘360 degree’ performance review conducted by the Engagement and Public Partnerships Director on behalf of, and in collaboration with, the Panel. If a Chair is appointed to the role during a second term as a Panel member, their tenure in the leadership role will be limited to one term of up to 3 years that will be completed within 9 years of joining the Panel.

The Panel will have two Vice Chairs: one focussing on Rare Conditions and one on Cancer. The Vice Chairs of the Panel will be appointed by the Chair and the Engagement and Public Partnerships Director following an open application process and must be eligible to be a Panel member at the time of appointment. Their initial term will be 3 years from the date of appointment, with the possibility of one further term following a successful ‘360 degree’ performance review conducted by the Engagement and Public Partnerships Director on behalf of, and in collaboration with, the Panel. If a Vice Chair is appointed to the role during a second term as a Panel member, their tenure in the leadership role will be limited to one term of up to 3 years that will be completed within 9 years of joining the Panel.

The Chair and Vice Chairs will be invited to the Genomics England Board once a year to discuss the Panel’s activities.

The Chair and Vice Chairs will be remunerated for 24 days per year, in line with Genomics England’s Non-Executive Directors and other committee Chairs. The Panel Chair is expected to work up to a maximum of 52 days per year and the Vice Chairs 30 days per year, of which the additional time required after the remunerated 24 days will be payable at the full-day rate for Panel activities.

Therefore, the expectation for the Chair is up to 28 additional days and Vice-Chairs is up to 6 additional days. This will be kept under review and revised as necessary.

4. Training

New Panel members will receive a welcome pack and induction training on joining the Panel.

Panel members may request training on any subject relevant to their effectiveness in their role as a representative of the people whose data is held by Genomics England. This may include the following:

* Key terms and concepts that are likely to come up in discussions, such as some basics of genomics, how health data is collected, stored and used; what different roles in genomics are and do (e.g. bioinformaticians);
* Operating structure of the NHS Genomic Medicine Service, insofar as it relates to patient and research participant experience, and patient engagement;
* Developments in the technology and analytical techniques underpinning genomics research (e.g. artificial intelligence and machine learning, long read sequencing, federating data, ‘omics’, and new approaches to phenotyping);
* Wider awareness of patient data use and associated challenges;
* Mainstream media and/or social media training;
* Communication and leadership training (e.g. how to speak to commercial researchers); and
* Wellbeing and mental health in patient advocacy.

A glossary of key terms will be maintained and updated when necessary, for the benefit of all Panel members.

Training requests will be appraised on a case by case basis by the Engagement and Public Partnerships Director and Head of Engagement, and in most cases, training will be provided by Genomics England itself, unless it is not something the company has expertise in.

The Panel may establish a regular ‘training’ slot in Panel meetings to cover new developments (e.g. in relevant technology or changes in the institutional landscape).

The Panel may wish to undertake an annual audit of its training needs, to inform a proactive training programme for its members, in partnership with relevant Genomics England colleagues.

5. Conduct

Panel members agree that they will not:

* Bring the Panel, and its role as an independent representative of patients, research participants and their relatives, into disrepute in any way.
* Share any confidential information about any matter that they have been privileged to access by virtue of their involvement with the Panel and/or Genomics England.
* Bring Genomics England into disrepute in any way. Complaints against Genomics England, either of individual staff members or the organisation as whole, should be raised directly with a nominated member of the Board.
* Engage with any media or press on behalf of Genomics England without discussion and permission from the Communications and Engagement team.

Any Panel member who deliberately does so will be required to stand down with immediate effect, at the request of the Panel Chair and the Director of External Affairs.

5.1 Nolan Principles of Public Life

Genomics England is a publicly funded body, and the Panel is here to represent the whole community of people whose data it looks after. Panel members are therefore expected to uphold the seven principles of public life (‘Nolan Principles’) whilst serving on the Panel. These are:

* Selflessness
* Integrity
* Objectivity
* Accountability
* Openness
* Honesty
* Leadership

Further details can be found here: <https://www.gov.uk/government/publications/the-7-principles-of-public-life/the-7-principles-of-public-life--2>

5.2 Engagement with the media

Panel members agree that they should not:

* On behalf of the Panel, offer any public endorsement of any new activities by Genomics England without discussing it first with the Panel Chair, unless the Panel has agreed that the development and delivery of the new venture has been directly underpinned by meaningful patient involvement (ideally in the form of co-creation with participants, patients and/or their families).
* Give any quotes to the media relating to Genomics England, its partners, or the work of the Participant Panel, without first discussing these in principle with the Panel Chair and Genomics England’s Communications Director.
* Comment in a public forum (including social media) on any disputes between NHS patients and their clinicians that relate either to the 100,000 Genomes Project or the Genomic Medicine Service.

5.3 Social media use

Panel members should avoid making any social media communications that could damage Genomics England or Participant Panel interests or reputation, even indirectly. This includes posting about business sensitive information that has been shared with the Panel in confidence. Any concerns should be raised in the first instance with the Panel Secretariat and the Panel Chair directly. Any misuse of social media should be reported to the Communications and Engagement team.

If Panel members are uncertain or concerned about the appropriateness of any statement or posting, they should discuss it with the Communications and Engagement team and the Panel Chair (if applicable).

5.4 Complaints

If a Panel member is concerned about the behaviour of a member of staff at Genomics England, the Panel member should contact the Panel leadership and Director of External Affairs (unless the complaint concerns the latter, in which case it would only be raised with the Panel leadership in the first instance).

Conversely, if a member of staff at Genomics England is concerned about the behaviour of a Panel member, they will raise this with the Panel leadership and/or Director of External Affairs.

6. Review

These Terms of Reference are effective from 1 February 2024 and will be reviewed by the Panel no less than 2 years from this date.