**Participant Panel Plan 2020**

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# **Mission**

The Participant Panel represents the interests of the thousands of people whose data is held by Genomics England. This includes the participants in the 100,000 Genomes Project, COVID-19 patients in the GenOMICC study, and NHS Genomic Medicine Service patients who choose to participate in ongoing research (via the ‘National Genomic Research Library’, NGRL), and will include others in the future (e.g. cancer cohorts in the Life Sciences Strategy).

We bring direct lived experience as patients or carers of people with rare conditions, COVID-19 or cancer. We work 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. We demonstrate our impact by strategically influencing the decisions made within Genomics England about who uses our sequenced genomes and associated health data, and what they do with it; and by helping Genomics England to engage with patients, participants, their families and the wider public in mutually beneficial ways.

The remit of the Participant Panel is to:

* Work collaboratively with Genomics England, helping to improve links between patients/participants and health researchers (from academia and industry) and clinicians
* Keep holding Genomics England to account for what they do with all the patient and research participant data they hold, seeking to ensure that data is being held safely and used for public good
* Continue to pursue results for the 100,000 Genomes Project participants and their families in perpetuity, including Additional Findings and pharmacogenomics results, keep chasing on behalf of any participants who have so far heard nothing at all, and make sure that the 100k cohort continues to benefit from advances in technology
* Provide advice to Genomics England on any aspect of their activities, upon request, based on our lived experience as research participants, patients and carers
* Encourage, and facilitate where possible, genomics-based research into rare diseases and cancer that embodies the principles of coproduction, where project participants/patients and their families can share the benefit of their lived experience if they wish

# **Future activities**

## *Panel meetings*

* The Participant Panel will continue to meet 4 times a year, at least some of these in person if possible, but also with a fully functioning videoconference option for anyone who would prefer not to travel to London.
* Dates will continue to be set on an annual basis wherever possible.
* Meetings will be expected to last for a full day (e.g. 10-4.30) and should typically be followed by an opportunity for relaxed discussions to continue.
* All Panel members will be encouraged to submit suggestions for sessions at Panel meetings; a draft agenda will be circulated at least 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 within 1 month of the meeting, and will include a list of Actions for follow-up at the next meeting

## *Scrutiny role*

* A ‘dashboard’ of key monitoring information requested by the Panel will be collated and circulated by Genomics England ahead of each Panel meeting, regarding the progress of its major programmes.
* This dashboard will be presented as a standing agenda item at each quarterly Panel meeting by the Chief Scientist or their nominated deputy.
* The dashboard will present the same information each time, for ease of monitoring. Typically it will include the following information for the previous quarter (and change from the quarter prior to that):
	+ an update on 100k participant progress (e.g. numbers of diagnoses reported to GMS; numbers of participants still waiting for a main result; number of Additional Findings reports generated/sent to clinicians; status of reviews of those participants waiting to be re-examined; any reanalysis, etc);
	+ recruitment breakdown of participants in the COVID study, and GMS patients who sign up for research, and [once this has been established] relevant monitoring metrics for these populations too. Wherever possible, we will ask for this to be broken down by health condition / subject area, ethnicity, geographic region, etc;
	+ research 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 GeCIP domain; link to lay summaries of these (where available).

## *Representing research participants at Genomics England*

* Panel members will continue to contribute to Genomics England’s work via participation in the following:
	+ Ethics Advisory Committee,
	+ Access Review Committee,
	+ GeCIP Board
	+ an effective new working relationship with the Commercial team (replacing the Discovery Forum).
* We will monitor the effectiveness of these groups, from participants’ perspectives, reporting any concerns back to the Participant Panel for consideration
* We will seek feedback about our effectiveness from the Chairs of these groups, as well as continuing to monitor our own performance and impact.
* Panel members will establish special interest ‘standing’ groups, for example on Cancer, on COVID-19 and on Patient/Participant Communications, to offer targeted input on these subjects to Genomics England on the basis of our expert lived experience. This may include attending extra videoconference calls and developing written materials where GEL and Panel members agree this would be useful.
* The Panel will respond positively to 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 the establishment of ‘task and finish’ groups, which will be supported by the Panel Secretariat where necessary.

## *Links with NHS Genomic Medicine Service*

* The Panel will establish a strong relationship with the ‘Genomics People and Communities Forum’ that is being set up by the NHS Genomic Medicine Service. The Participant Panel Chair (or nominated deputy) will sit on the Forum, and the Forum Chair will 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.

## *Communicating with participants / patients whose data is held by Genomics England*

* The Panel will establish a ‘front door’ via the Genomics England website, which will enable 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 we have (ARC, EAC, GeCIP Board, etc) and what outputs/impacts we can demonstrate;
	+ submit questions/comments to the Panel directly;
	+ hear about any vacancies on the Panel;
	+ find links to relevant Genomics England project updates/GeCIP activity that might be of interest to them (including contact details for the GeCIP lead); and
	+ express their interest in working with a specific GeCIP as a patient/participant representative.
* The Panel Secretariat will be asked to provide the necessary technical support. It would be useful to create a sub-group from the main Panel to oversee the content and operation of this ‘front door’.

# **Panel membership**

* The membership of the Participant Panel will continue to reflect the communities we are here to serve. Consequently, this means we will evolve to include reps from the GenOMICC COVID study, and GMS patients who consent for their samples to be added to the National Genomic Research Library (NGRL) held by Genomics England. We will aim to appoint 2 representatives from each of these new cohorts by July 2021
* All Panel members will be appointed on a three-year term, with the possibility of extension by mutual agreement with the Director of Engagement or Panel Chair.
* Will continue to be drawn from as wide a demographic and geographic area as possible, including the home nations if applicable (wherever GEL gets its participants from)
* New members will be appointed following a successful interview with Director of Engagement or Panel Chair
* Silent members (who have not attended more than 3 main Panel meetings in a row, and don’t contribute anything between meetings) will be thanked for their time and stood down from the Panel (unless there are exceptional circumstances e.g. parental leave, as agreed with the Chair)
* Members wishing to stand down may do so at any time by notifying the Chair and the Secretariat of their decision.
* Future versions of this Plan may introduce a maximum term limit for Panel membership.

## Chair and Vice Chair roles

* The Chair of the Panel will be elected by the Panel members, and must be [eligible to be] a Panel member at the time of election. His/her initial term will be 3 years, with the possibility of one extension following a successful ‘360 degree’ performance review conducted by the Director of Engagement on behalf of, and in collaboration with, the Panel.
* The Vice Chair of the Panel will be appointed by the Chair and the Director of Engagement following an open application process, and must be [eligible to be] a Panel member at the time of election. His/her initial term will be 3 years, with the possibility of one extension following a successful ‘360 degree’ performance review conducted by the Director of Engagement on behalf of, and in collaboration with, the Panel.

## Training requests

* 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 / concepts that are likely to come up in discussions: basics of genomics and how health data is collected, stored and used; what the different roles 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 / involvement activity)
	+ Developments in the technology and analytical techniques underpinning genomics research (e.g. AI and machine learning, long read sequencing, new approaches to phenotyping, etc)
	+ Wider awareness of patient data use, (e.g. recent initiatives such as OneLondon), and associated challenges
	+ Mainstream media and/or social media training
	+ Communication training (e.g., how to speak to commercial researchers)
* A glossary of key terms will be maintained and updated when necessary, for the benefit of all Panel members
* 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)

## Unacceptable conduct

Panel members will not:

* On behalf of the Panel, offer any public endorsement of any venture by Genomics England, unless the Panel agrees that the development and delivery of the venture has been directly underpinned by meaningful patient engagement (ideally in the form of co-creation with participants, patients and/or their families)
* Give any quotes to the media relating to Genomics England or the work of the Participant Panel, without first discussing these in principle with the Panel Chair and/or Genomics England’s Head of Communications (Yufan Chen)
* 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
* 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 we have been privileged to access by virtue of our involvement with the Panel / Genomics England

Panel members who deliberately do any of these things will be required to stand down with immediate effect, at the request of the Panel Chair and the Director of Engagement.

# **Review**

This Plan is effective from October 2020 and will be reviewed by the Panel no less than 3 years from this date.