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Participant Panel Strategy For 2025/2026

The Participant Panel holds a vital position within the governance structure of Genomics England. It advises the Genomics England Board and is actively involved in decision-making across various committees.

Genomics England and the Participant Panel maintain a close partnership, ensuring participants' interests remain central to all activities. Within this relationship, founded on mutual respect, the Panel consistently holds Genomics England to account by providing constructive challenge. Members achieve this by contributing their lived experiences and unique perspectives, directly influencing how Genomics England operates and, crucially, guiding decisions regarding access to and use of participant data.

United by a commitment to help everyone benefit from genomic healthcare, Genomics England and the Panel collaborate on strategic directions. As Genomics England develops its future strategy, the Participant Panel has established its key priorities for the upcoming year to align with and support these shared goals, with these priorities subject to annual review.

**The Participant Panel’s Key Strategic Aims for 2025-2026:**

1. **Improve participant experiences through effective communication.**
2. **Promote greater public and patient involvement and engagement (PPIE)[[1]](#footnote-1) in research using the National Genomic Research Library (NGRL).**
3. **Strengthen the Participant Panel’s ability to advocate for participants across all Genomics England initiatives.**
4. **Ensure the Participant Panel is involved early in major Genomic England initiatives and key decisions.**

**1.0 Improve participant experiences through effective communication**

**1.1 Better information sharing**

The Participant Panel wants Genomics England to communicate more effectively with participants – especially about how their data is used, research outcomes, success stories, and the role of Diagnostic Discovery in enabling more diagnoses.

To support this, the Participant Panel will encourage Genomics England to develop a wider communications strategy, such as:

* Creating a dedicated section on the website to share information and news with participants;
* Sharing content and stories through various channels including social media;
* Strengthening links with patient advocacy/ support organisations and with Genomic Medicine Service Alliances (GMSAs) to improve information sharing;
* Holding a workshop with the Participant Panel to explore better ways to communicate with 100,000 Genome Project participants.

The above would be delivered within the remit of the Communications & Engagement Working Group and will be used to inform meeting agendas on an ongoing basis.

**1.2 Building stronger connections**

The Participant Panel will explore ways to connect with various groups such as the GMSA Patient and Public Voice (PPV) Panels and patient advocacy/ support organisations. These connections can help build a stronger, more informed genomics participant and patient community.

**2.0 Promote greater public and patient involvement and engagement (PPIE)[[2]](#footnote-2) in research using the NGRL**

**2.1 Clearer understanding of PPI**

The Participant Panel will advocate for a clearer explanation of what public and patient involvement and engagement really means – particularly the difference between *involvement* (including co-production), *engagement* and *participation* in research.

**2.2 Meaningful Involvement**

The Participant Panel will continue advocating for participants, patients and carers to be meaningfully involved throughout all stages of the research cycle, wherever possible, to ensure their views genuinely influence decisions and outcomes. This includes:

* Encouraging Genomics England to develop a clear plan that helps researchers connect with participants and patients, for example, through patient advocacy/ support organisations;
* Supporting the creation of resources, such as a guide, to help researchers involve patients and the public ethically and effectively;
* Ensuring PPI remains a key priority in the Access Review Committee (ARC) and Research Network Committee (RNC), among Research Network community leads, and at the annual Genomics England Research Summit (GERS);
* Promoting more accurate ways to measure public and patient involvement (and engagement) in NGRL-based research through Genomics England’s annual research project audits.

**2.3 Improving access to PPI**

The Participant Panel will continue advocating for better ways of engaging participants, patients and carers, so they can easily find information about research relevant to their condition and opportunities to get involved in shaping that research.

* 1. **Strengthen the Participant Panel’s ability to advocate for participants across all Genomic England initiatives**
  2. **Honouring commitments**

The Participant Panel will ensure Genomics England keeps its promises to participants, including:

* Continuing to seek answers for 100,000 Genomes Project participants;
* Following through on offering ‘additional findings’ to BRIDGE participants who gave consent;
* Applying key learnings from these pioneering projects to future ones, such as the Generation Study;
* Seeking to improve cancer outcomes by providing more accurate diagnoses that will guide personalised treatment plans.
  1. **Making the Participant Panel more inclusive**

The Participant Panel will work to increase the diversity of its membership by:

* Encouraging broader representation, including participants with rare conditions or cancer, and those recruited through initiatives like Diverse Data and the Generation Study;
* Reaching under-represented and historically marginalised communities, including people of different genders, ages, LGBTIQ+ identities, disabilities, those from diverse ethnic and socioeconomic backgrounds - especially those with limited access to genetic services or unique genetic variations, and those who are primary carers for vulnerable/ disabled children and or vulnerable/ disabled/ elderly people**;**
* Developing inclusive recruitment strategies by connecting with community groups and individuals to make joining the Participant Panel easier and more welcoming;
* Ensure that all digital and written communications shared between Genomics England Limited, the Participant Panel and all external PPIE organisations, are fully accessible and comply with WCAG v2.2 guidelines / Equality Act 2010 requirements, where possible.

**4.0 Ensure the Participant Panel is involved early in major Genomics England initiatives and key decisions**

**4.1 Early and ongoing involvement**

The Participant Panel will advocate for early engagement in new Genomics England initiatives, as well as regular updates, to ensure all participants are fairly represented from the beginning.

* 1. **Supporting outreach to under-represented and historically marginalised communities**

The Participant Panel will work with Genomics England to ensure that diverse data and voices are represented in genomics research and related initiatives. This includes:

* Sharing best practices;
* Advising on outreach and engagement strategies;
* Providing feedback on existing strategies to improve their impact.

1. Briefing notes for researchers - public involvement in NHS, health and social care research (2021): <https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research#tab-256881> [↑](#footnote-ref-1)
2. Briefing notes for researchers - public involvement in NHS, health and social care research (2021): <https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research#tab-256881> [↑](#footnote-ref-2)