# Summary of the Participant Panel meeting

## 5 December 2024

The meeting opened with an introduction from the Participant Panel Vice-Chairs, who welcomed new members and the incoming Chair, while acknowledging the contributions of outgoing members stepping down.

Key updates from the Executive Leadership Team highlighted Genomics England’s participation in the upcoming Festival of Genomics (January 2025), plans for the Genomics England Research Summit (June 2025), and the Participant Panel’s involvement in both events.

Led by the Airlock team, the first session provided an overview of data access models, highlighting why Genomics England uses a ‘protected access’ approach in its Research Environment. Discussions centred on the ethical and secure use of participant data, including how access requests are reviewed. All applications are assessed by the Access Review Committee (ARC) and/or Research Management Team against ARC-defined criteria to ensure legal and ethical compliance. The Airlock Committee sets the standards for reviewing requests to export files from the Research Environment, and the Airlock Team applies these standards to individual requests. The team highlighted the importance of balancing support for research with maintaining strict privacy and security standards.

The Diagnostic Discovery team outlined how clinically relevant (‘actionable’) findings are shared with NHS laboratories through the Diagnostic Discovery pathway to benefit participants. Discussions covered the process of continually re- examining participants’ genomic data held in the National Genomic Research Library (NGRL), the criteria NHS scientists use to review findings, and the importance of informing participants about new findings and discoveries. A notable recent breakthrough discussed was the discovery of a non-protein coding gene called RNU4-2 linked to childhood neurodevelopmental disorders, demonstrating the power and impact of genomics research.

The Chief Executive Officer (CEO) shared Genomics England’s plans to:

* Enhance data accessibility for research: Genomics England aims to streamline data pipelines, making it easier for researchers to access high-quality data.
* Support the NHS: Explore ways to reduce the turnaround time for genomic analyses.
* Improve participant diversity: The Diverse Data Initiative is recruiting participants from underrepresented communities to create more inclusive datasets.

The CEO also discussed how Genomics England’s work complements initiatives like Our Future Health, ensuring a collaborative approach.

During the Panel-only session, the discussion focused on improving participant engagement. Members discussed Genomics England’s latest efforts to understand the priorities of patient advocacy groups and charities, and its communication channel audit that will help shape its future communications and engagement strategy. The Panel stressed that collaboration with patient groups and charities is crucial to reach participants within their communities.

Panel members reiterated the need to enhance engagement and communication with 100,000 Genomes Project participants. They suggested strengthening collaboration with patient groups, charities, and GMSAs. However, they emphasized that identifying the specific wants and needs of participants and key stakeholders is an essential first step.

The meeting concluded with updates from the various committees and groups on which some Panel members sit:

* Members of the Research Network Committee discussed how they had met with Research Network Community Leads to discuss how to enhance public and patient involvement in genomic research using participant data in the NGRL.
* The Communications and Engagement Working Group and the Access Review Committee discussed plans to fill upcoming member vacancies.