# Summary of Participant Panel Meeting Minutes

25 September 2024

The meeting began with a Panel-only session, led by the Vice Chair for Rare Conditions. This session provided an opportunity to reflect on feedback gathered from Panel members over the summer, as well as from those who have recently stepped down. The insights gathered will inform the development of the Panel’s future strategy and help refine its ways of working. A summary of this discussion was later shared with Genomics England.

Genomics England provided an update on the Generation Study. The discussion focused on the information and support needed to enable parents to participate in the study, and efforts to recruit a sample that is broadly representative of England’s population, with an emphasis on supporting recruiting sites to better engage with communities often underrepresented in research. As the Generation Study recruits newborn babies, the sample is expected to be more reflective of the birth population, rather than the entire population of England.

Panel members shared updates on their involvement with other Genomics England committees, including the Access Review and Research Network Committees. A key highlight from these committees was the ongoing effort to embed meaningful patient and public involvement in genomic research using the National Genomic Research Library (NGRL).

The Panel was introduced to Genomics England’s newly appointed Caldicott Guardian, who plays a crucial role in ensuring the ethical use of participant data. The Panel expressed interest in ongoing discussions around data access and consent, emphasising the importance of continuing this dialogue.

Genomics England’s Communications Team shared an update on projects led by the Communications and Engagement Working Group—a collaboration between the Communications and Engagement team and the Participant Panel. These projects include efforts to continue improving accessibility in Genomics England’s communications and strategies, to enhance participant engagement with research using NGRL data, particularly through sharing more participant stories.

The Panel continued discussions with Genomics England’s Chief Executive Officer and Chief Digital and Strategy Officer regarding the organisation’s future strategy. The Panel emphasised the importance of patient and participant engagement in shaping Genomics England’s future strategic priorities, and the need to maintain trust.

The meeting concluded with a discussion on the Panel’s next steps and the evolution of its role in partnership with Genomics England. Looking ahead to the next meeting, the Panel identified the Airlock procedure as a key topic for discussion. This system is designed to protect the privacy and security of participant data when it is transferred in or out of the Research Environment.