Summary of Participant Panel Meeting on 19 March 2025

The meeting opened with an introduction from the Chair and from the Director of External Affairs at Genomics England.

Led by the Chief Medical Officer and Director of Translational Genomics, the first session was a presentation on the clinical genomic testing pathways in response to Panel members’ queries about this. An overview was provided of the genomic testing journey within the Genomic Medicine Service, outlining the key steps from a patient’s initial health concern to the return of results by a clinician and the role of different organisations within this. A discussion followed which included: the way in which genomic findings are reported and the role of NHS clinical scientist teams; data protection within the National Genomic Research Library (NGRL); how new gene-condition association discoveries are incorporated into clinical practice; and managing the small number of duplicate records within the NGRL. The Panel was also given an update on Genomics England’s ongoing process of Diagnostic Discovery and heard that potential new genomic diagnoses continue to be returned to the NHS every month.

The Panel considered an update on the Diverse Data Initiative, which was funded by the government in Spending Review 2021 to improve representation in genomic research and address health disparities in seldom heard communities. The Initiative has focused on key areas such as sickle cell, maternal health and pre-term birth, equity in health research, and emerging technologies and methods. Following the update, the discussion focused on strategies for engaging seldom heard communities. It was noted that Genomics England funded thirteen public and patient involvement and engagement (PPIE) proposals from recruiting sites for sickle cell as part of the Improving Black Health Outcomes BioResource collaboration to support awareness and research participation. The discussion considered Genomics England’s broader community engagement strategy, with Panel members emphasising the importance of building trust. Panel members suggested engaging faith and community groups to encourage participation, highlighting that engagement efforts must extend across England.

The aim of the next session of the meeting was to engage Panel members at an early stage in the development of Genomics England’s long term policy on exporting artificial intelligence (AI) and machine learning (ML) trained models from the research environment. This is currently not allowed. Panel members were asked for their views on the potential benefits and risks of permitting this in future, ahead of a more in-depth discussion at the next Panel meeting to help advise Genomics England on the approach it should take.

The Panel considered a briefing on data security and protection by the Senior Information Risk Owner and Director of Assurance for Genomics England. This included an overview of cybersecurity measures, including monitoring and detection systems, multi-factor authentication, and collaboration with the National Cyber Security Centre. The importance of data protection and compliance with the Data Protection Act was reiterated, ensuring participant data remains secure.

The Panel heard updates from members who sit on the Access Review Committee, the Ethics Advisory Committee, the Research Network Committee and the Medicines and Healthcare products Regulatory Agency (MHRA) Yellow Card Biobank Patient Advisory Group. Of particular note was a presentation on accessibility by Panel members who are part of the Communications and Engagement Working Group, highlighting its importance in communications and emphasising that it benefits everyone, not just those with disabilities. Clear and simple language, alternative text for images, and good contrast were recommended to improve accessibility for printed materials and websites.

Finally, the Panel discussed initial plans for the design of a programme of engagement during 2025/26 to explore public and healthcare professional attitudes to the use of genomics for the adult population to support predictive, preventative healthcare. The Panel noted that this remains subject to government approval. The Panel commented on the importance of exploring how people want pharmacogenomic information returned to them; the role of digital tools in its delivery, and of healthcare professionals interpreting results; and the importance of empowering people with access to their own records whilst considering ethical issues around privacy and family impact. Panel members encouraged Genomics England to engage early with the relevant professional governance bodies and with key stakeholders.

The meeting closed with a discussion with Genomics England’s Chief Executive. Panel members took the opportunity to raise questions about the impact of the recent announcement about the abolition of NHS England and about progress with the Rare Therapies Launch Pad.