**Summary of the Participant Panel Meeting on 18 June 2025**

The meeting opened with a warm welcome from the Chair and Executive Leadership. They reflected on the recent, highly successful Genomics England Research Summit, noting its strong attendance and high levels of participant engagement. The Panel’s contributions were widely praised, reinforcing the value of keeping participant voices at the heart of all future events.

The Panel watched a new, short film introducing the Participant Panel and its work. Panel members were thanked for their involvement in its creation. Discussion focused on how the film could be used. The Communications and Engagement Working Group – including Panel members and Genomics England staff – will decide this.

The Panel heard an update on the interim policy for using artificial intelligence (AI) and machine learning (ML) models within the Research Environment. At present, models can be brought into the Research Environment to be “trained” – which means teaching the model to learn from the data there. However, once trained, the models themselves cannot be taken out. Testing results and other outputs can be taken out, as long as they follow strict Airlock rules. These rules make sure that only safe, approved information leaves the Research Environment.

The Panel was asked whether this policy should stay the same or change. Questions and concerns included the risk of misuse if models were exported, the need for strong safeguards, and the importance of openness and clear governance. Members agreed it would be useful to involve those with relevant expertise in future decisions. A future meeting will look more widely at the ethical, legal and governance issues around access to data in the National Genomic Research Library.

An update on the Cancer Programme highlighted how whole genome sequencing can benefit people with cancer by improving diagnosis, guiding treatment, and identifying eligibility for clinical trials. The Panel discussed the complexity of the cancer testing pathway, including the role of Genomic Tumour Advisory Boards, which bring together different specialists to interpret results and advise on treatment.

It was noted that whole genome sequencing can be especially valuable for people who have run out of standard treatment options, as it may open up access to clinical trials. Target genes linked to clinical trials are already being added to the National Genomic Test Directory to help match patients with suitable studies.

Questions were raised about consent processes, how cancer data is included in the National Genomic Research Library, and whether information about whole genome sequencing is available and accessible to people who have just been diagnosed.

Genomics England's Chief Executive gave an update on recent developments, including reflections on the Genomics England Research Summit and government funding processes. He highlighted the importance of Diagnostic Discovery and Genomics England’s role in supporting the NHS, cancer services, and the Generation Study. Panel members asked about the impact of international developments on genomic research, ethical issues linked to gene editing, and future participant recruitment plans.

The Panel discussed a presentation on the research into polygenic risk scores. This provided an overview of how these scores can help predict the risk of common conditions and support earlier diagnosis, screening, and tailored treatment. They will increasingly be used in clinical practice and research studies using data in the National Genomic Research Library.

The Panel explored issues around ethics, data privacy, equitable access, and how polygenic risk scores might be used in routine care. Ongoing research and policy development was highlighted to address these concerns. Members asked for a follow-up discussion on the legal and ethical aspects of polygenic risk scores, as well as more detail on Genomics England’s plans for a future adult population research study.

Updates on two recent engagement projects were shared. The first gathered insights from patient advocacy groups to shape Genomics England’s communications and engagement strategy. The second brought together resources to help researchers involve and engage patients and the public – including participants in the National Genomics Research Library - in their work. Panel members stressed the importance of co-production and involving people early in the research process.

Genomics England's Chief Medical Officer gave an update on Diagnostic Discovery, noting that Genomics England sends candidate diagnoses to the NHS each month, and that work is ongoing to improve tools so that this can be done more quickly and at scale. The Panel emphasised the need for clear communication to explain this ongoing review of participant data and to keep the wider participant community informed.

Finally, Panel members shared updates from their involvement in other Genomics England committees, working groups, and public and patient involvement groups. They highlighted the importance of building stronger links with the Patient and Public Voice Groups within NHS Genomic Medicine Service Alliances to support future collaboration.