
September 2026

Genomics, Healthcare and You

Engagement Programme
Executive Summary



**Hopkins
Van Mil**



Executive summary

This report brings together key findings from the [engagement programme](#) on Genomics, Healthcare and You commissioned by Genomics England in October 2025. The engagement programme explored attitudes towards the potential use of genomics in routine, preventive healthcare for adults, in particular [pharmacogenomics \(PGx\)](#) and the return of [actionable risk findings](#) on common conditions. Individual reports give the detailed findings from each of the three engagement strands. Films about the programme, created by Paul Wyatt films, share some participants' views from the inclusive communities and public dialogue strands.

Pharmacogenomics (PGx)

Using genomic information to identify the potential for adverse drug reactions and/or to determine which drugs and medication dosages may be most effective for individuals based on their genomic profile.

Actionable risk findings

Findings are actionable when they identify risks for conditions that can be prevented, treated, or managed more efficiently, especially when detected early.

About the programme

Genomics England has been funded by government to deliver a large-scale adult population genomics research study. This [research study](#) aims to sequence the genomes of 150,000 adults to assess how genomics could be used in routine, preventive healthcare. This is set out in the NHS 10 Year Health Plan for England and the Life Sciences Sector Plan.

Genomics, Healthcare and You was commissioned to ensure that diverse public and healthcare professional perspectives and expectations shape the design of the research study before it begins.

The questions that the engagement programme set out to explore were:

1

What are diverse public and community perspectives on the use of adults' genomic information to improve prevention or early detection of ill health and personalise medication?

2

What values and principles do people apply, and what do they find important, when they consider how and why genetic information could be used and returned during their lifetime for these purposes?

The engagement programme ran from October 2025 to June 2026 and comprised three distinct engagement strands, delivered in the following order:

- Healthcare professional (HCP) engagement with 181 HCPs across an online survey and workshops, delivered by RAND Europe, focusing on primary and community care;
- Inclusive community engagement with 83 participants from ethnically diverse communities in Bradford, Birmingham and East London, led by The Social Agency, People Street and The Leap, using community-led, place-based methods;
- A [public dialogue](#) with 112 participants broadly reflective of the population of England, delivered by Hopkins Van Mil (HVM) using deliberative methods guided by Sciencewise principles, held in London (for London and South East participants) and Newcastle (for Newcastle and North East participants).

At the conclusion of all three strands, a sense-making workshop brought together 36 participants from across the engagement strands to validate headline findings and identify cross-strand priorities. Findings from all four sources inform this overarching report.

The overarching finding: conditional optimism

Across all three strands, and confirmed in the sense-making workshop, the response to genomics in healthcare is one of conditional optimism. Participants and HCPs could see clear potential, particularly in PGx. There was overwhelming consistency across the three strands of the programme in what participants identified as important to them about the study. Participants expressed optimism for a health system that pivots towards preventive health, which they saw as an important outcome for embedding genomics in healthcare.

Support was expressed consistently, contingent on four conditions:

- Genomic data being used only for health purposes;
- Benefits reaching all communities equitably;
- The NHS being adequately resourced, trained and structurally ready to deliver the study;
- Trust being built through transparency, representation and honesty on the limitations as well as the benefits of the study.

Participants, facilitators and speakers at the London public dialogue workshop



These conditions are fundamental to the substance of what the research study needs to address in order to secure the hopes participants in the engagement programme expressed for it.

The context for genomics in healthcare

Participants from all three strands of the engagement programme situated genomics firmly within their lived, or professional (in the case of HCPs), experience of the NHS and the current political and social climate. Participants did not believe genomics could be isolated from broader social and political contexts. Public dialogue participants connected their concerns about genomic data to wider anxieties about political uncertainty, the influence of powerful interests, and the precedent set by events like the Windrush scandal for discrimination. Inclusive community participants described direct experiences of discrimination and dismissal within healthcare that shaped deep scepticism. Healthcare professionals flagged workforce pressures, fragmented infrastructure, and the risk that genomics could be seen as a solution to problems that are fundamentally about inequality and resources.

Research study design, recruitment and communication must start from what is known about public understanding of the health system as well as genomics. This means that the research study should acknowledge the NHS context honestly as genomics will operate as part of that system.

Attitudes to the two research study applications

PGx attracted strong support across all three strands of the engagement programme (HCPs, inclusive communities and public dialogue). Its benefits felt tangible and personal. These include getting the right medication the first time, avoiding adverse reactions, and reducing the trial-and-error that erodes confidence in

both medicines and clinicians. Participants in the inclusive communities strand valued PGx as a source of agency, as information they could use to advocate for themselves in consultations with the medical profession. HCPs saw PGx as a tool to improve prescribing, reduce waste, and strengthen the therapeutic relationship. 76% of surveyed HCPs identified personalised care as the top positive outcome.

Support for the return of [actionable risk findings](#) was more conditional across all three strands. Genomics feels fixed and certain in a way that for example a cholesterol reading does not. For many a risk result can feel like a diagnosis-in-waiting. Of the conditions explored in the public dialogue and some of the inclusive community sessions, participants were more supportive of the return of risk findings for cardiovascular disease and cancer where treatment pathways were more certain and the evidence clearer. For those conditions with more uncertainty on interventions and treatments, such as dementia, receiving a risk result was widely seen as more of a burden rather than a benefit.

[Polygenic risk scores](#) (PRS) were broadly viewed with more scepticism. Many HCPs reflected that they do not yet have the evidential basis for widespread clinical use. Both the public dialogue and inclusive communities strands independently concluded that PGx should be the primary initial focus of the study, with actionable risk developed more cautiously as the evidence base strengthens.

Trust, equity and participation

Trust was the theme participants returned to most consistently across the entire programme, and the sense-making workshop confirmed it as the precondition for participation. All three groups approached the question of trust at three distinct levels: trust in the study itself; trust in Genomics England as a data steward; and trust in the wider ecosystem of data use and governance.

What undermines trust differs by group but converges on a common set of concerns:

- direct experience of discrimination and dismissal within healthcare;
- the risk that medical research will again be designed primarily for white European populations at the expense of or to the exclusion of other populations and thus potentially exacerbating inequities in research and healthcare;
- the risk of mission creep in data use by taking the use of genomic data outside healthcare and health research, along with the possibility that commitments made now could be reversed by a future government.

What builds trust was also consistent across strands:

- honesty over reassurance;
- representation in genomic data and in governance structures;
- future-proofing data protection measures;
- and transparency about data flows including who has access to the research data and how it flows within the NHS.

The lack of diversity in existing genomic databases was raised as both a scientific limitation and an equity issue across all three strands. Participants felt strongly that striving for diverse and representative data is a design requirement for the study. The sense-making workshop added that proactive action to address misinformation, cultural sensitivity around faith and family associations with DNA, and a commitment to close the feedback loop, telling research participants what had changed as a result of their engagement, are also essential.

Data storage, use, access and consent

The idea that genomic data is categorically different from other health data came up unprompted across all three strands of the engagement. It is permanent, it reveals

information about family members who have not necessarily consented to take part in the study, and genomic data cannot be changed for protection if there is a data breach. The implications for storage security, access controls and governance were drawn explicitly by participants in all groups.

Participants in all three strands consistently said that genomic data must be used only for health purposes. Use by government agencies for immigration or policing, by employers or insurance companies were all identified as redlines. This was a non-negotiable across the programme and was confirmed in the sense-making workshop.

Consent was the topic that generated the most sustained discussion in the sense-making workshop. Participants want consent to be meaningful and ongoing rather than a single moment when joining the study. They want the ability to update preferences, withdraw at any stage, and be informed about how their data is being used. The distinction between de-identified research data held in the National Genomics Research Library and individually identified clinical findings was not initially clear to participants in any strand. As a result, many said that this information needs to be explained visually and clearly at the point of consent. Participants also raised specific concerns about what happens to data if the study loses funding, and about the mechanisms that would exist to restrict or revoke data access if the political landscape changes significantly.

Study design, return of findings and wider ecosystem readiness

The practical questions of how the study should be designed, how findings should be returned, and what the NHS needs to have in place received sustained attention across all three strands and in the sense-making workshop.

On the return of findings, participants drew a clear distinction between findings that are lower stakes, where a letter or NHS App

notification is acceptable, and elevated risk results, which require a personal conversation with a named clinician. HCPs described pre- and post-test counselling as best practice, drawing on family history genetics services as a model. They also raised concern about whether the study, and any future roll-out of genomics in healthcare, is deliverable at scale within an already stretched NHS. During the course of the engagement programme it was explained to participants that polygenic risk scores (PRS) is not within the scope of the study, but it was discussed and explored by participants as part of their conversations about risk.

On communication, participants believe that building awareness of the study requires layered, multi-channel approaches using trusted messengers for example, community champions, faith leaders, GPs and peer researchers. They also called for community language content, and honest messaging that does not overstate what genomics can currently deliver. There were concerns that digital-only approaches will miss older generations and those with limited digital access. The sense-making workshop confirmed that hospital staff and NHS professionals should be active recruitment and communication channels.

On system readiness, HCPs said the study's ambitions are likely to only be realisable if NHS infrastructure is fit for purpose. This means:

- Genomic findings being integrated and embedded into existing clinical systems, not added to a new platform which HCPs and patients will have to navigate additionally;
- Nationally standardised guidelines in place before roll-out;
- Role-specific training embedded in undergraduate education and delivered to the existing workforce in time;
- Sustainable rather than study-based funding, with a clear ability to close the study down safely, including protections for genomic data, should funding come to an end.

Recommendations

The following recommendations emerge from an analysis across all three strands and the sense-making workshop, organised by the three lenses used throughout this report (for the research study; for Genomics England as data steward; for the wider ecosystem). Some of the recommendations overlap across the three elements.

For the research study

- Focus the initial phase on pharmacogenomics and develop actionable risk more cautiously, and only as the evidence base justifies it;
- Design consent to offer genuine choices, with:
 - the ability to update preferences over time;
 - a human alternative to digital consent;
 - consideration given to a prospective opt-out mechanism for specific health uses.
- Develop a return of findings pathway that guarantees access to support for elevated risk results;
- Use multi-channel, layered communication with trusted messengers and community language content;
- Build diverse participation as a design requirement from the start, with active outreach and over-representation of underrepresented communities where needed;
- Inform the NHS workforce about the study so that hospital staff, GPs, nurses and pharmacists are able to signpost patients to information and guidance.
- Explore the role of community pharmacy as a point of access for information, consent conversations and referral as part of discussions on the wider roll-out of the research study;

- Treat conditions with an existing treatment pathway as the primary focus for actionable risk;
- Build in a clear exit strategy for responsible wind-down if funding for the study ends prematurely, or if any future implementation of genomics in healthcare is curtailed, with clarity on what happens to participants' data;
- Develop a plan to communicate findings back to participants in this engagement including information on what changed as a result of sharing their views, what was acted on, and what was not.

For Genomics England as data steward

- Prohibit non-health use of genomic data within its research programmes;
- Develop and publish clear, visual explanations of the two data pathways: de-identified research data in the NGRL and the return of clinical findings;
- Adopt an ongoing consent model that enables participants to update preferences and withdraw at any point;
- Proactively explain the role of pharmaceutical and biotech companies and what access they do and do not have to genomic data for research and development purposes;
- Treat data diversity as a headline design requirement with public

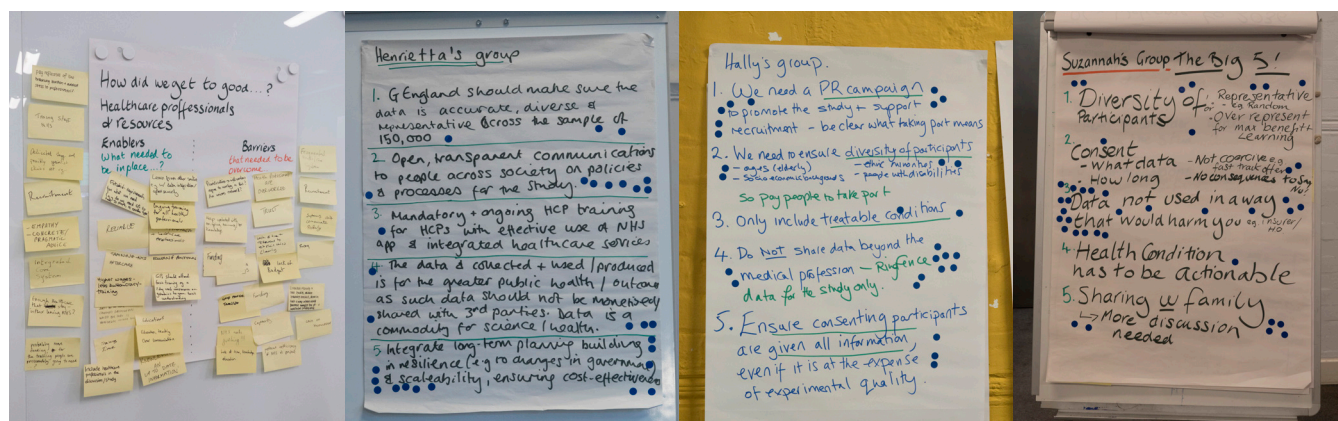
commitments to address this, acknowledging current limitations honestly, and reporting on progress;

- Actively communicate Genomics England's existing track record in responsible genomic data stewardship to build more trust than generic reassurances can;
- Put in place governance and leadership informed by a wide range of public perspectives, with ongoing accountability and publicly reported outcomes.

For the wider ecosystem

- Integrate patients' genomic data into existing NHS clinical systems with embedded, interoperable functionality;
- Develop nationally standardised guidelines and clinical pathways before any future roll-out of genomics into routine healthcare;
- Begin role-specific training, embedded in undergraduate education for medicine, nursing and pharmacy, and delivered to the existing workforce in time to match any potential roll-out of the research study once it is complete;
- Provide sustainable funding for the research study and any future roll-out of genomics in healthcare;
- Address systemic access barriers e.g., digital exclusion, language barriers, health literacy, and deprivation proactively and by design.

Flip charts from the London public dialogue workshop listing participants' recommendations.



Conclusions

The Genomics, Healthcare and You engagement has demonstrated that diverse publics and healthcare professionals are conditionally supportive of the use of genomics in preventive healthcare. There is genuine goodwill, grounded in direct experience of how current healthcare falls short, and a real desire for the study to succeed. Support for the study, and any future roll-out, is conditional on the foundations being right with safeguards on data access, benefits reaching all communities, and the NHS supported to deliver the programme.

A consistent message across all three strands is that this engagement should not be seen as a stand-alone research and engagement programme, but rather the beginning of a relationship. Communities made it clear they are willing to continue to engage, but will be watching whether Genomics England acts on what it has heard. Participants from all three strands asked, at the close of the sense-making workshop, to be told what has changed as a result of their participation. They believe that the commitment to close the loop is in itself an act of trust-building which would demonstrate a meaningful exchange between Genomics England and those who will be affected by the integration of genomics in healthcare.

The convergence of views across very different groups, confirmed by participants themselves when they heard each other's findings for the first time in the sense-making workshop, is significant. Participants were clear about what success would look like for the research study:

- Beginning with PGx and building towards actionable risk and the use of PRS as the evidence strengthens;
- Making sure the research study is equitable, inclusive and accessible reflecting the diversity of England's population by design;
- Findings returned with a guaranteed human option and embedded support;
- A constitutional commitment from Genomics England that beyond clinical use for individuals, data will only be used for health-related research purposes;
- Sustained engagement with those involved in this engagement programme sharing what has been learnt and how this is informing the work of the study, Genomics England more broadly and what comes next.

A strong and recurring hope expressed throughout the Genomics, Healthcare and You engagement is that genomics will form part of a genuine shift from a treatment service to a prevention service. Participants believe this is important work, which should be supported.

Participants in the East London Inclusive Communities workshops.



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Images by Paul Wyatt and People Street

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