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Genomics, Healthcare and You

Overarching Engagement
Programme Report



**Hopkins
Van Mil**



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Foreword

Genomics England

A year after the NHS 10-Year Health Plan for England and the Life Sciences Sector Plan set out a bold ambition for genomics to support pre-emptive, personalised care and treatment, this report offers a timely opportunity to consider what that ambition could mean in practice.



Dr. Natalie Banner
Chief Ethics and Engagement
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These plans position genomics as one of the innovations that could help usher in a new era of secondary prevention, with the potential to enable people to gain greater insights into their health. They also outline the intention to deliver a new large-scale study sequencing the genomes of 150,000 adults to assess how genomics could be used in routine preventive care. This study, alongside other existing Genomics England-led programmes, will provide a backbone of evidence and supporting digital infrastructure to position the UK as a leader in genomics-enabled prevention and diagnostics.

For Genomics England, this ambition builds on more than a decade of work in partnership with the NHS demonstrating the value of genomics in cancer and rare conditions, including through the 100,000 Genomes Project. This work remains central to Genomics England's mission.

It also marks an important shift: from applying genomics in rare condition and cancer settings, cancer or contexts where people are already seeking a diagnosis or receiving treatment, towards exploring how genomic information could support earlier intervention and prevention across adult populations, before a condition is diagnosed. For example, using pharmacogenomics to inform the choice or dosage of medicines for patients, or identifying genomic risk of certain conditions where pre-emptive steps can be taken to reduce risks going forward.

This shift presents enormous potential. Just as with other major shifts in healthcare, to harness its potential will require us to explore complex questions, including what information should be returned, to whom, when and in what format; how uncertainty should be explained and managed; how genomic data should be used over time, governed and protected; what support people and families may need; and whether the system and workforce are ready to support implementation.

Building on the expertise we have built and lessons learnt from our previous programmes such as the 100,000 Genomes Project and the Generation Study, we see a key element of our work as exploring these questions and putting ethics, equity and public engagement at the heart of our work.

This report focuses on the findings from Genomics England's Genomics, Healthcare

and You engagement programme. We commissioned and partnered with a consortium of expert research agencies and community organisations to deliver this wide-reaching engagement programme, aligning with Genomics England's commitment to equity-driven and engagement-led genomic research.

The programme sought to understand public and healthcare professional views on genomic information becoming a more routine part of healthcare for adults without a known, genetically caused or influenced condition. It also explored the hopes, concerns, red lines, enablers and barriers that should shape any future approach. Through this programme we engaged members of the public from across England broadly representative of the English population, and communities that have historically been underserved or excluded from genomic research. We also engaged healthcare professionals, focusing mostly on those working in primary and community care, where genomics will play a greater role as it becomes a part of preventative healthcare.

What we heard was both encouraging and challenging. Participants saw real potential for pre-emptive genomic testing to support the shift from sickness to prevention, give people greater agency over their health, and strengthen relationships between healthcare providers and patients. However, their optimism was conditional on building trust, embedding equity and ensuring that both the NHS and wider system context are carefully considered in design and implementation.

We are grateful and humbled by the openness and trust shown by everyone who took part. Their contributions are already helping us think more carefully about the design of an adult population genomics research study and Genomics England's wider strategy.

This report speaks to the opportunities and challenges of data stewardship, trust-building, uncertainty, consent, communication, equity, and system readiness.

At its heart, it reminds us that the future of genomics will not be shaped by technical possibility alone, but should be developed with the people it is intended to serve in mind, and in ways that are worthy of their trust and confidence.

Glossary of terms

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.

Adult Population Genomics Research Study (known as “the study”): The research study that will be delivered to generate evidence and digital infrastructure on the benefits and implementation of population-level genomic testing in healthcare.

DNA: DNA is a molecule found in all living things. It carries the genetic information we need to survive.

Gene: A gene is a section of DNA that contains a specific instruction. This instruction provides information about how we develop, function and grow.

Genome: A genome refers to the complete set of our genes. Humans have about 20,000 genes in their genome.

Genomics: Genomics concerns the study of a person’s genome, including gene functions, interactions, and structure. In the context of healthcare, genomics can tell us about how our genes affect our health, particularly concerning rare conditions and cancer.

The Genomics, Healthcare and You engagement programme (known as “the engagement programme”): The three-strand project to engage healthcare professionals; communities in Bradford, East London and Birmingham; and public dialogue participants from across English society in discussions to inform the design of the research study. In this report, we refer to these collectively as the engagement strands.

Healthcare professionals (HCPs): Members of the medical, dental, pharmacy and nursing professions and any other persons who in the course of their professional activities may administer, prescribe, purchase, recommend or supply a medicine and/or work with patients in a therapeutic capacity. The HCP strand of the Genomics, Healthcare and You engagement programme focused primarily on professionals drawn from primary and community care settings (including general practitioners, community pharmacists, practice nurses, and people working in public health) alongside family history clinical nurse specialists across different settings.

Monogenic risk: Monogenic risk refers to a (usually rare) high risk change(s) in a single gene contributing to the development of a condition.

The National Genomic Research Library (NGRL): A secure database and bioresource managed by Genomics England in partnership with the NHS that holds samples, genomic data, clinical data and other associated research data provided by participants in Genomics England’s programmes and the NHS Genomic Medicine Service (GMS).

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.

Polygenic risk scores (PRS): Uses information from someone’s genome to estimate the contribution of genetic risk to a specific condition. It combines the individual risk associated with each genetic change to estimate their overall effect. This estimate can account for thousands of genetic changes that have a small effect. Polygenic and monogenic risk can be combined to give the overall contribution of genetic risk of developing a condition.

Public dialogue: A robust and tested approach to involving citizens in decision making. Dialogues bring together a diverse mix of citizens with a range of views and values, and relevant policy makers and experts, to discuss, reflect and come to conclusions on complex and/or controversial issues.

Public engagement: The umbrella term for ways of involving the public in decisions, policy or research that affect them.

Whole genome sequencing (WGS): The technique that allows researchers to identify and look at a person’s entire genome.

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, cancer and dementia where treatment pathways were more certain and the evidence clearer. For those conditions with more uncertainty on interventions and treatments, 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

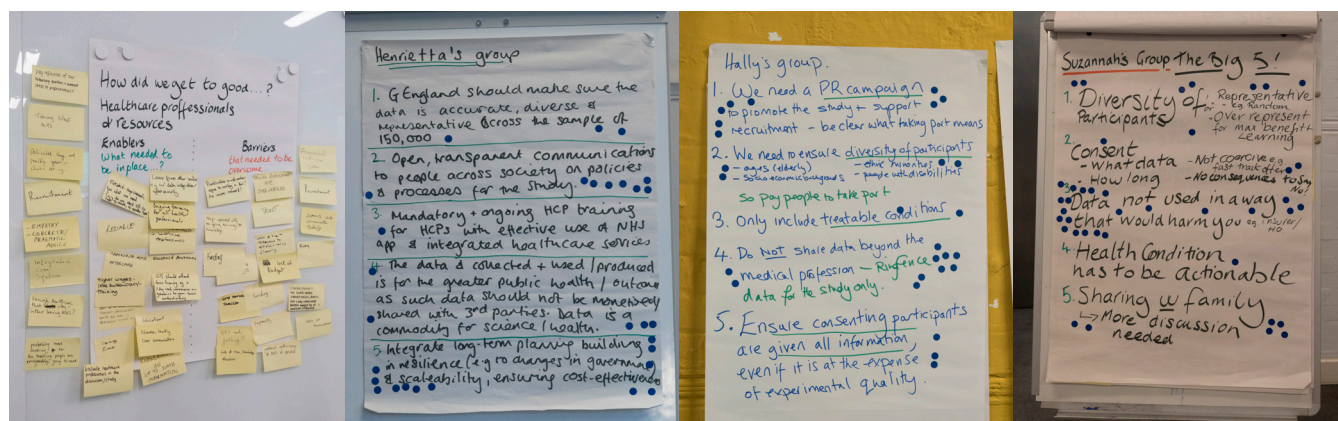
commitments to address this, acknowledging current limitations honestly, and reporting on progress;

- 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.

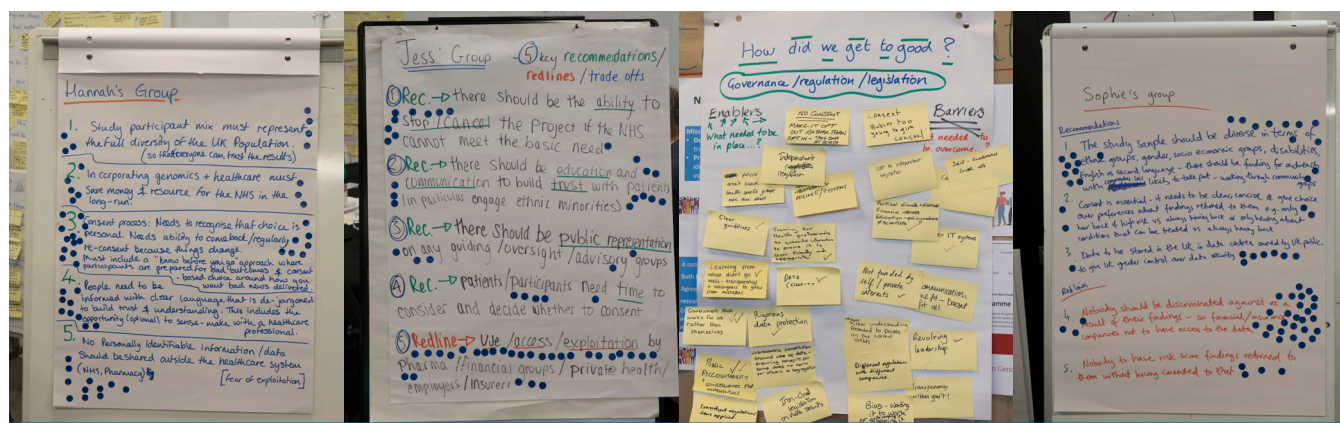
A consistent message across all three strands is that this engagement should not be seen as a stand-alone research and engagement programme, but rather the beginning of a relationship. Communities made it clear they are willing to continue to engage, but will be watching whether Genomics England acts 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.

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



1 Introduction

This chapter gives the background, aims and objectives for all three strands of the Genomics, Healthcare and You engagement programme. It describes the context in which the programme was developed, explains Genomics England's role as the commissioner of this significant engagement programme and introduces the work done by the partners.

1.1 Background to the engagement

When Genomics England was set up to deliver the 100,000 Genomes Project in 2013, its focus was on exploring the role whole genome sequencing could play in the diagnosis and treatment of rare conditions and cancers. Since 2018, the NHS Genomic Medicine Service has enabled whole genome sequencing (WGS) to be offered as standard to people and their families with a range of conditions and clinical presentations, always in the context of people coming into the healthcare system with symptoms or a treatment need. WGS is then used to seek an explanation for the underlying genetic variation(s) that could explain those symptoms or help determine the best treatment pathways.

Genomics England has now been funded by government to explore the potential for a [research study](#) within a wider [research programme](#), and to carry out initial design work. This is set out in the NHS [10 Year Health Plan for England: fit for the future \(GOV.UK\)](#) and the [Life Sciences Sector Plan \(GOV.UK\)](#), which references a large-scale study to sequence the genomes of 150,000 adults and assess how genomics can be used in routine preventive care.

1.2 What the engagement set out to achieve

This programme of engagement, [Genomics, Healthcare and You](#), was commissioned in October 2025 and delivered by a partnership led by [Hopkins Van Mil \(HVM\)](#). The three-strand programme included:

- Engagement with healthcare professionals (HCPs) led by [RAND Europe](#)
- Inclusive communities approaches led by [The Social Agency](#), [People Street](#) and [The Leap](#)
- Public deliberations led by HVM referred to in this report as the public dialogue.

This report is the concluding output from Genomics, Healthcare and You. It sets out the overarching findings and common themes from the full programme. A three-lens approach has been used for this summary report in which the implications for the study, for Genomics England as data steward, and for the wider ecosystem are set out. This report also draws on the detailed findings from each strand of the programme, which are set out in individual stand-alone reports. Reporting also includes a set of films created by [Paul Wyatt Films](#), in which participants reflect on the process and the findings of the [public dialogue](#) and elements of the [inclusive communities](#) strand.

Genomics, Healthcare and You aimed to inform the:

- Design of the research study;
- Broader implementation of Genomics England's long-term strategy to bring genomic research and medicine into the wider healthcare system.

An oversight group (Appendix A) was established to advise and challenge the process. This process was also supported by a sub-group of The Participant Panel at Genomics England. The programme was managed by a project team comprising Genomics England and the programme partnership.

Each of the three strands of Genomics, Healthcare and You explored people's attitudes in two main scenarios:

Pharmacogenomics (PGx)

This means using genomic sequencing 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.

Returning findings on actionable high risk of some common health conditions

This is in line with the Government's ambition to focus on early identification and intervention for individuals at high risk of developing common conditions.

Participants also considered **polygenic risk scores (PRS)**. A PRS uses information from someone's genome to estimate the contribution of genetic risk to a specific condition. It combines the individual risk associated with each genetic change to estimate their overall effect. This estimate can account for thousands of genetic changes that have a small effect. Polygenic and monogenic risk can be combined to give the overall contribution of genetic risk of developing a condition.

The overarching questions explored in Genomics, Healthcare and You 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?

In addition, questions were considered around:

- People's views about being offered and receiving genomic findings that could be used to personalise their medication?
- People's views about being offered and receiving genomic information about their future health risks?
- If people do want to receive these genomic findings, how would they want this to happen and with what information and support?

Genomics England will use the findings from this programme to ensure the research study and the broader research programme strategy is shaped by diverse perspectives and public expectations.

This report sets out the strong convergence of views expressed across the findings from each engagement strand.

2 Methodology

This programme used robust engagement and deliberative methods with trusted design and delivery principles throughout. Detailed explanations of how the engagement was run for each strand are contained in the individual reports [link], this chapter provides a summary of the processes. The next section provides the [cross-strand themes](#).

2.1 Overview of the programme approach

The Genomics, Healthcare and You engagement programme used three distinct but complementary methodologies to engage with healthcare professionals (strand 1); communities under-represented in health research (strand 2); and a public group (strand 3) broadly reflective of the population of England.

The partners: HVM, RAND Europe, The Social Agency, People Street and The Leap came together to propose this approach due to common values and principles, which include a strong commitment to:

- Thoughtfulness and humanity in all our work;
- Involving those who are traditionally excluded from policy, and who are often most affected by decisions made at a policy level;
- Sharing power with those involved, never being extractive or tokenistic, building trust in the process;
- The responsible delivery of genomics in healthcare, informed by the voices of people across society;

- The principles applied to the programme were agreed at an inception meeting with Genomics England held in October 2025:
 - Starting from where people are and supporting all participants in their journey through the programme;
 - Informing without overwhelming participants on a complex, multi-faceted programme;
 - Using creative and innovative methods to reach those who have been traditionally excluded, or who will find it harder to engage e.g. busy HCPs;
 - Accounting for a range of cultures, practices and lived experience of healthcare;
 - Ensuring the contribution participants make in time, commitment and significant engagement is recognised;
 - Enabling participant-led exploration and questioning of the issues.

A summary of each of the approaches is set out in Figure 1.

Figure 1: An overview of engagement processes

Healthcare professionals

- A survey (131) complete responses
- 13 online workshops/interviews with 50 HCPs
- In 2 phases: role-based followed by systems workshops
- Focus on primary and community care roles
- Analysis using descriptive statistics (survey and inductive/deductive thematic coding (workshops)



Inclusive communities

- Community-led, place-based approach
- Working with trusted local networks
- Taking an intersectional approach to engage 83 participants from underrepresented, ethnically diverse communities from Birmingham, Bradford and East London
- 3-month scoping phase with the communities followed by a day-long workshop in each area
- Methods tailored to each community



Public dialogue

- Deliberative methods
- 112 participants, broadly reflective of the population of England, drawn from London & the South East and Newcastle & the North East
- Taking part in an online briefing and working within a dedicated online space
- Groups in London and Newcastle took part in two in-person weekends in their regions
- Specialist input across four workshops on genetics, PGx, risk and ethics
- Analysis of the data resulting from these discussions to produce qualitative findings



In addition, on completion of all the engagement strands a 'sense-making' workshop was held online. This brought together 36 participants from across the three strands. This enabled participants to discuss what was most important from their strand of the engagement with participants from the other strands. This workshop was an addition to the original methodology. It needed to ensure each engagement strand did not draw conclusions in isolation. It acted as a validation and sense-making session with participants reviewing the headline findings across strands, generating a further layer of participant-led insight to inform this summary report.

Participants from the London workshops.



A panel of expert speakers at the London workshop



Overarching cross-strand themes

3 The context for genomics in healthcare

Across the three strands of Genomics, Healthcare and You it is clear that participants' reflections on genomics are shaped by their broader experience of the NHS, of data use across public institutions, and of the current political, social and geopolitical climate. The summary of findings in this chapter reflects that genomics cannot be seen in isolation and how people's attitudes are informed by connections to the wider ecosystem.

3.1 Genomics does not operate in isolation

All three groups of participants placed genomics firmly within a wider context, not as a standalone technology or medical application. This matters because participants framed their perspectives on genomics healthcare as being shaped by trust in institutions, experiences of inequality, and anxiety about how personal data is used across the public sector, not just in health research.

There is a strong desire across all three strands for genomics to succeed, particularly in creating a pivot to a more preventive approach to healthcare. However, they are all alert to how overstretched the NHS is. This leads to a concern that it will struggle to ensure the benefits from this innovation in healthcare are accessible to all.

This points to the need for Genomics England to embed equity into the research study design from the beginning.

Healthcare professionals

HCPs framed their concerns around the NHS itself, a system they described as challenged, and struggling to implement even routine innovations. Public health professionals, in particular, noted a risk that genomics could distract from addressing the social determinants of health (housing, environment, poverty) that they saw as having a greater immediate impact.

HCPs were also alert to genomics being positioned as a solution to problems that they believed were fundamentally about resources and inequality.

Inclusive communities

This wider context was most acutely seen in the inclusive communities strand. Participants described direct experiences of discrimination and dismissal within and beyond healthcare that shaped scepticism about genomics in healthcare. The Birmingham workshop intentionally opened with a structured listening session to hear these histories before participants engaged with the study design. Concerns about eugenics, immigration data misuse, and stigma around disability and consanguinity: close biological relatedness, such as between family members, were

grounded in lived experience, not abstract theory. As a result, the key question for many participants in this strand was focused on whether Genomics England and the wider system can be trusted to deliver genomics enabled healthcare without doing harm to some communities.

Public dialogue

The context of an underfunded, overstretched NHS was front of minds for many public dialogue participants, drawing on their own experience. Many also connected their thinking to wider political uncertainty. This included concerns about immigration rhetoric, data misuse, and the growing influence of powerful elites (especially in the US) on UK policy. Participants were explicit that these concerns were not separate from their views on genomics. The Windrush generation was cited as an illustration of how personal data could be misused.

There was somebody in the previous group who was saying that her grandparents came here as part of the Windrush generation, and she was saying with all the deportations that are happening, her concern was that if her genomic data was on a database, could that one day at some point be used to find people who someone feels doesn't have a right to be in the UK or whatever?

Participant, public dialogue, Newcastle

There was a consistent call to future-proof genomics policy against political change. Participants also hoped genomics would accelerate a genuine shift from treatment to prevention, but worried that funding might be diverted away from other key NHS services to achieve this.

Sense-making workshop

The gathering of cross-strand participants at the sense-making workshop confirmed and sharpened this wider perspective.

Many participants named digital exclusion as an important issue. They were specifically concerned about the risk that older people, people without smartphones, and communities with lower digital literacy would be structurally excluded from the study if it relied heavily on the NHS app.

Another barrier for people who already face the most barriers.

Participant, Sense-making workshop

In addition, a few in the sense-making workshop shared a fear that younger generations carry a distinct form of institutional mistrust. They saw this as rooted in a general, accumulated scepticism about government and the NHS. As a result, they suggest that the research study should be intentional in its engagement of younger people, working with them to build trust.

But we have to take accountability of the younger generations as well, because a lot of systemic mistrust stems from them, because the younger generation doesn't trust the NHS, doesn't trust the government to make capable decisions for them.

Participant, Sense-making workshop

Many participants raised concerns about over-stating what genomics can currently deliver or presenting it as an answer to everything. One participant described not wanting genomics to be treated like AI, "the AI-ification of everything" where the excitement around a new tool or development leads to the neglect of proven approaches.

3.2 What this means for genomics and healthcare

What this means for the research study

Design and communication must start from where participants actually are, not where the research study hopes they will be. Participants in all three strands approached the research study through the lens of their existing experience of the NHS. This is an institution and a system that they value, whether as employees or as a member of the public, but that they also find it stretched, fragmented and, at times, unequal. Despite this, participants believe the research study must be embedded in the NHS, that it cannot be delivered outside this system.

Research study materials, recruitment communications, and consent processes need to acknowledge this context honestly. These resources must show how the work of the research study can be integrated into the NHS so that it can be delivered equitably and without further draining NHS resources.

What this means for Genomics England as data steward

The credibility of Genomics England cannot be assumed, particularly from the perspectives of the inclusive communities and public dialogue strands whose participants are largely unaware of its work or track record. All three strands placed genomics within a broader landscape of concern about how health and personal data is used and potentially misused: by commercial interests, by public bodies, and by future administrations with different values. The research study design needs to consider how it will build trust in its use of data through specific and tailored action. This should include honest communications about the potential advantages and limitations of genomics in PGx and risk, highlighting Genomics England's previous research studies with rare conditions and cancer, and newborn screening as a demonstration of trustworthiness.



Small group discussions at a London public dialogue workshop.

What this means for the wider ecosystem

The question around whether the NHS infrastructure can encompass the integration of genomic medicine is, for participants, a prerequisite for the research study being able to deliver equitably. Participants across all three strands were worried about the risk that genomics, in a fragmented and under-resourced system, would leave some people in society behind. They raised specifically the need for:

- Training for healthcare professionals;
- Developing clinical systems that are interoperable and can speak to each other;
- Ensuring that primary care is properly resourced with the time and possibility to support people to act on genomic findings.

These are important to ensure the promise of personalised, preventive healthcare can be delivered.

For many, investment in the wider health ecosystem is not optional; it is the condition under which the potential benefits of the research study can, in time, accrue to the wider population.

4. Attitudes to the research study applications

Attitudes across the three strands to the two specific use cases, pharmacogenomics (PGx) and return of findings on actionable risk are explored in this chapter.

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

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.

All three groups considered the potential for genomics in healthcare with cautious optimism, whilst being able to see hopes and challenges. Genomics felt both “important but risky” to participants in the inclusive communities strand; “amazing and scary” to public dialogue participants, and as something which is “exciting” but also something to be “apprehensive” about to healthcare professionals. A significant shift was also observed in the inclusive communities strand and in the public dialogue from participants perceiving genomics to be immovable and deterministic to becoming one more piece in the health jigsaw puzzle.

participants in the HCPs strand described PGx as a tool that could improve patient engagement, reduce wasted prescriptions, and build trust in the therapeutic relationship. Community pharmacists were particularly enthusiastic about this development for these reasons.

I get a lot of patients asking what side effects they might get when starting a new medication, and all I can say is that we won't know until you try it but to get a personalised insight into risks of particular side effects or likelihood of efficacy would be really valuable.

Open text survey response

4.1 PGx: the strongest area of support across all strands

PGx attracted consistent support across the HCPs, inclusive communities and public dialogue strands for distinct but mutually reinforcing reasons set out below:

HCPs

76% of survey respondents saw personalised care as the top positive outcome, with 63% citing more accurate prescribing. Workshop

Inclusive communities

Participants shared vivid personal accounts of the medicines they had been prescribed which included life-threatening reactions to codeine; ineffective antidepressants; and long lists of side-effects. These direct experiences made the case for PGx concrete and compelling for participants. The prospect of empowerment and agency within healthcare was particularly valued by participants in the inclusive communities strand. They felt they had often been told

what to take rather than engaged in a discussion about what would be appropriate.

I was told what to take by my GP and had very little choice. [PGx] is a good thing as it could give us more agency.

Participant, East London



Participants at an Inclusive Communities workshop in East London.

Public dialogue

The benefits of PGx felt clear and objectively positive to participants. Many had direct experience of trial-and-error prescribing, adverse reactions, or medicines that simply had not worked for them. The prospect of getting the right medication first time resonated strongly. As in the inclusive communities strand, some participants, particularly those who had felt dismissed in interactions with clinicians in the past, valued the potential to advocate for their own care using PGx information that they could carry with them on the NHS App for example.

Sense-making workshop

Many participants reinforced a point made mostly in the public dialogue workshops, that there is a risk that genomics could reinforce a 'drug-first culture'. Once a genetic basis for a condition was identified, medication could be prescribed automatically at the expense of lifestyle advice or social prescribing.

4.2 Return of findings on actionable risk: qualified support

Support for return of findings on disease risk was more conditional across all three strands, with attitudes being determined by both certainty and actionability of the findings. In each strand there were distinctions between participants' reactions to the return of findings in relation to personal risk, and on Genomics England and NHS's responsibilities in returning the risk findings. Participants in all strands are broadly more comfortable with, and accepting of, PGx than risk scores as applications of genomics in healthcare.

HCPs

HCPs raised specific concerns about patient anxiety when receiving uncertain or incidental findings. They raised the potential lack of guidance and support for those receiving risk information or communications about risk. Of particular concern, given the context described in the previous chapter, is the potential for unmanageable healthcare system capacity pressures as a result of the return of findings. Participants described pre- and post-test counselling as recommended best practice, but equally raised acute concern about whether this model is deliverable at scale, either for the research study or any subsequent roll out of the programme.

Inclusive communities

It is important to note that when participants in the inclusive communities strand discussed risk in abstract terms, they clearly understood that it was not diagnosis. However, when asked to imagine receiving a risk result personally, some shifted their thinking to believe that they would find a risk score much more akin to a diagnosis. This potential conflation of risk and diagnosis must be taken into account in the design of the research study, ensuring that there is support available to work through what a risk score actually

means. Some participants said they would prefer not to receive results for conditions with no effective treatment.

Public dialogue

For some participants, genetics feels fixed and certain in a way that a cholesterol reading does not. For many participants a high-risk result can feel like a diagnosis-in-waiting. Information about actionable risk was shared with participants in the following forms: scenarios, expert speaker presentations and panel discussions. Three health conditions were chosen to explore attitudes: cardio-vascular disease, dementia and cancer. The heart disease and dementia case studies included both monogenic and polygenic risk scores. The cancer case study focused on monogenic (e.g. Lynch syndrome). Heart disease was seen as the most straightforward and acceptable condition to receive a risk score for, because clear actions and preventive treatments exist. Cancer discussions often focused on the potential to tailor screening based on risk scores. Dementia raised the most concern, given the absence of a cure or proven ways to slow its progress.

Some participants expressed the view that receiving a risk score could be demotivating, as genomic information could feel deterministic, leading people to believe they cannot do anything to change their outcome. This could affect people who have a high risk of a condition, or indeed people who have a low risk and, as a result, decide they have no health concerns and do not need to worry about exercising or eating a balanced diet.

Participants pointed to middle age and the existing NHS Health Check as a sensible point of entry for the delivery of risk findings. Polygenic risk scores were seen as needing more evidence before guiding health decisions and being included in any return of findings.

Sense-making workshop

The workshop strongly confirmed PGx as the most accessible and welcome application for genomics in healthcare. In terms of risk, participants confirmed that polygenic risk scores need a more cautious approach than PGx. Caution was also called for in relation to conditions with more uncertainty on intervention options.

4.3 What this means

What this means for the research study PGx

The findings across all strands make clear that participants are most comfortable with PGx as a valuable application for genomics in healthcare with genuine benefits for HCPs and patients alike. This suggests that PGx could be the primary focus for initial stages of the research study because benefits feel tangible and personal:

- Getting the right medication immediately avoiding the trial-and-error current approach;
- Avoiding adverse reactions;
- Avoiding medicines wastage which is a drain on resources and patient confidence.

Across all three strands support for PGx was consistent and grounded in direct experience.

Actionable risk findings

Findings suggest that actionable risk findings require a more careful and phased approach. The research study should be designed to be clear where there is the evidence to support a more certain risk score, and where there is not. This should also be made clear in all research study communications. Support pathways including counselling where needed, follow up, and clear and personalised communications need to be in place before risk findings are returned. The situation where support pathways are developed in response to a demand once the research study is underway

is to be avoided as it would be undermining trust and future support for the work. Keeping public trust in mind as the research study develops is critical to creating a well-designed approach.

What this means for Genomics England as data steward

There is a specific and serious responsibility for Genomics England to be clear about the current limits of genomic risk, particularly what existing data can and cannot reliably tell us about risk in people of non-European-ancestry populations. Participants were told that the genomic databases on which risk scores and pharmacogenomic profiles are currently built are predominantly derived from people of European ancestry. For participants from other backgrounds, genomic information may be less accurate. This was extremely important to participants in all engagement strands, both as a scientific limitation and an equity issue.

Overstating what the research study can currently deliver on the basis of unrepresentative data would cause mistrust. There are hopes that the research study could

increase the diversity of genomic data available, thus building trust. Honest, proactive communication about these limits, alongside a clear commitment to addressing them through diverse data collection would be a very positive approach.

What this means for the wider ecosystem

It is clear to participants that the ambition of returning actionable risk findings to participants at scale will only be realisable if the NHS has the infrastructure to support what comes next. Across all three strands, participants were clear that a risk result without a clear action, access to a clinician who can explain it, and a support pathway, is more of a burden than a benefit. The issues raised by participants about an overstretched, under-capacity and under-resourced NHS support the view that system readiness should be treated as a precondition for delivering genomics in healthcare at scale. The question of whether the NHS can absorb what the research study generates (and any future roll-out if the evidence supports it), needs to be answered as this work is funded and planned for.

Participants at the London public dialogue workshop.



5 Trust, equity and participation

This chapter begins with what undermines and what builds trust. It continues with participant reflections from across the strands on data diversity and trustworthiness for the research study, for Genomics England as data steward and across the wider ecosystem. The chapter then shares how the sense-making workshop builds on these points and ends with the implications across the three-lenses of this report.

5.1 What undermines trust, and at which level

Trust in the research study

In the inclusive communities strand, participants described direct experiences of discrimination and dismissal within healthcare that generated scepticism about whether this research study will be designed for, or benefit, them and their communities. The sense that medical research has historically been designed for white European populations, at the expense of, or to the exclusion of, other populations was a live one. Participants in both the inclusive communities strand and the public dialogue were fearful that this research study could perpetuate this pattern. Concerns were also raised by some participants that PGx could be used in the research study as a mechanism for quick-fix prescribing. They thought it could lead to an over-reliance on medication rather than genuinely listening to patients and considering alternative routes such as changes to lifestyle or diet.

Trust in Genomics England as data steward

The risk of mission creep with data shared for healthcare purposes being repurposed for other public sector purposes, or for commercial interests, was one of the most acute concerns raised in the public dialogue. The Windrush generation was cited as an illustration of how identity and health data

can be weaponised. HCPs flagged that if they cannot answer patients' questions about data security, patients are likely to seek answers elsewhere from less trusted sources such as on social media. Developing trust in how data is collected, stored and accessed is therefore seen by participants as fundamental to Genomics England's role.

Trust in the wider ecosystem

Participants in all three strands were concerned about the broader landscape of data use and misuse. They reflected on commercial exploitation, public sector data access, and the possibility that commitments made now could be reversed by future governments without the same commitment to the safeguarded use of genomics. This concern is grounded in the current political climate, and hearing about developments in other countries, particularly the United States. Societal commitments to trustworthy uses of genomics and genomic data for public benefit are key.

5.2 What builds trust

Across all three strands, the same conditions for trustworthiness were named:

Honesty over reassurance

Participants explicitly stated their preference for frank acknowledgement of data security limits, the uncertainty inherent in the return of

risk findings, and gaps in existing databases. They believe that overpromising and underdelivering would be deeply damaging.

Representation in data and in governance

Underrepresented communities need to see themselves reflected in the genomic database, and in the teams and structures governing it. Tokenism was explicitly rejected. The public dialogue called for over-representation in the research study, in genomic research and in genomic datasets where needed for equity.

Constitutional protection

The strongest and most consistent message from both the public dialogue and inclusive communities is that genomic data must be protected by a legal framework or constitution against decisions by any future government to allow use of genomic data which crosses participants' red lines.

Visual, layered transparency

Visual representations of data flows for example, where genomic data goes, who can access it, what they can and cannot do with it, were seen as really helpful and effective, particularly for participants in the inclusive communities strand. Participants want to know that the distinction between generating clinical findings for individual patients and storing de-identified genomic data in the National Genomic Research Library (NGRL) for research purposes are separate functions with the research study. They understood that this needed explanation during the dialogue. As a result, transparency on the difference between de-identified research data in the NGRL, and clinical findings needed to be actively explained to the wider public.

5.3 Genomic data diversity as a design requirement

All three strands raised the lack of diversity in existing genomic databases as a significant concern. This is simultaneously a scientific limitation and an equity issue as raised here:

- Black African participants in Birmingham described the under-representation of non-European-ancestry data as reinforcing a sense that health systems have not been “not designed with them in mind.”

Representation across the whole process. Researchers need to represent Black people. Not Tokenism

Participant, Inclusive Communities, Birmingham



Participants at a Birmingham workshop.

- HCPs were aware that polygenic risk scores and some PGx profiles derived from predominantly European-ancestry data may be less accurate for patients from other ancestral backgrounds. They see communicating this limitation honestly as part of their responsibility, and of Genomics England's.
- The public dialogue called for over-representation of underrepresented communities in data collection in the research study and in genomic datasets in general, not just proportional representation, to meaningfully address historical gaps, although there was some doubt about whether this would ever be possible.

We've always felt underrepresented, so it's like, how do you get to the root cause of that problem? You know, you can put up all these ads and try to persuade people, it's just all surface stuff, I don't know how much that's going to really work in practice.

Participant, Public dialogue, London

Those involved in the engagement programme believe the research study should make specific design efforts to be inclusive for study participants from a range of currently under-served communities and ensure results returned are sufficiently accurate for them.

5.4 Trusting enough to take part

All three engagement strands show that participation in the research study is contingent on trust being established, not assumed. For the inclusive communities strand, this means:

- Continued meaningful engagement through trusted local networks: this engagement programme shouldn't be seen as an end, but a beginning;
- Embedding the use of mother tongue into communications as needed;
- Demonstrating how community input has shaped the research study before asking for data;
- Genuine feedback loops that show Genomics England is listening and acting on what it has heard.

For public dialogue participants, willingness to participate rests on consent being genuine, not a tick-box exercise. It is also contingent upon knowing data will only ever be used for health purposes and for public benefit. They want to know that they can have confidence that benefits will reach all communities and not just those already well-engaged with, or served by, healthcare.

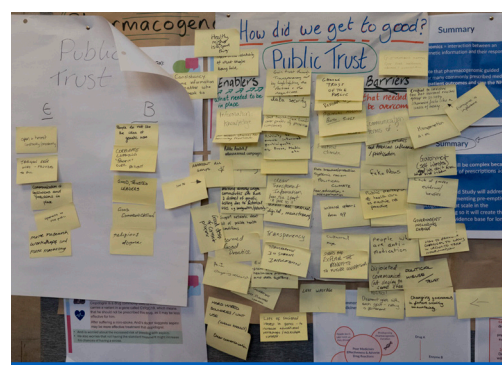
For HCPs, participation in the programme, as professionals delivering it depends on adequate training, clear information pathways, and recognition that their time and capacity are finite.

5.5 Sense-making workshop focused points

Trust was the theme participants returned to most consistently in all discussions in the sense-making workshop. The workshop confirmed that trust is a key element in participation in the research study, and that mistrust comes from lived experience of health research as well as healthcare.

Like in the past, so many things have happened that had breached that trust. So, trust, honesty, is needed for the study. There will be conspiracy theories, there will be false news and all of that. So, how to overcome those to make the study as transparent as possible.

Participant, Sense-making workshop



Participant reflections on trust

Participants across all strands independently described trust as needing to be actively earned through action, consistency, and honesty by Genomics England in the research study and as a data steward. Trust, equity and participation in the research study were all drawn out by participants in the sense-making workshop as key themes for Genomics England to consider. The following points highlight the areas participants wanted to build on from the parts of the engagement programme that they had taken part in. Participants stressed the need for the research study to:

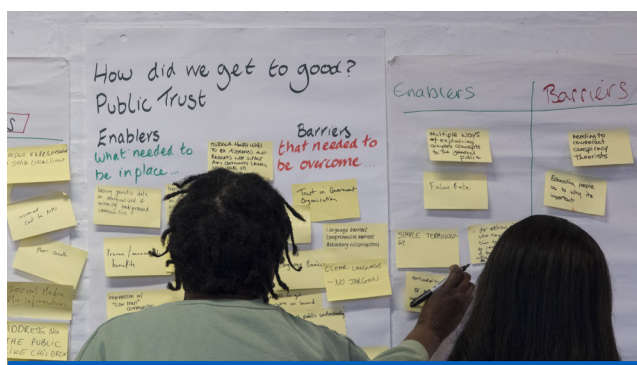
- Actively address misinformation about genomics on, for example, social media, ensuring evidence-based information reaches potential research study participants;

- Be aware of and understand the faith-based and family-cultural concerns that can generate reluctance to participate in a genomics focused research study;
- Take an inclusive and equitable approach to research study design which is intersectional, focusing on all communities historically and currently underserved by health research;
- Build on the confidence many have in Genomics England's track record in delivering responsible research studies using genomic data;
- Embed a feedback loop with participants in the engagement programme so that they know their views have been heard and to understand what has changed as a result of their input.

5.6 What this means

For the research study

Participants across all engagement strands want to see a commitment from Genomics England to continue as they have with this process – to embed equity and effective representation into research study design from the beginning. This would apply across all activities including how participants are recruited to the research study; how information about the research study is communicated in the consent materials and when findings are returned.



Participants at a London public dialogue workshop



Participants at an East London Inclusive Communities workshop

For GEL as data steward

Participants expect Genomics England to ensure that the collection and use of data is safeguarded for the specific purposes of the research study, not accessed for other non-health purposes. Some participants approve the use of their data for the research study, but not for inclusion in the NGRL for wider research purposes. Others were open to the use of their data for facilitating scientific discovery and as such welcomed the inclusion of the data in the NGRL. Value was placed on the development and publication of clear, visual explanations of data flows and governance mechanisms. As already stated in the report it is important for everyone that data diversity is seen as a key requirement within and for genomic research databases.

For the wider ecosystem

There is value in Genomics England convening cross-sector learning on inclusive engagement. This could focus on building on the Genomics, Healthcare and You engagement strands to share knowledge of methods which genuinely engage people from across society in health research and a future with genomic medicine.

6. Data storage, use, access and consent

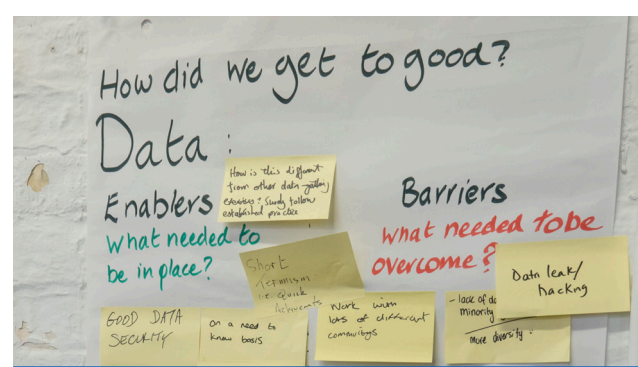
Whilst this has been referred to in other parts of this report, this chapter addresses how participants in all three strands think about the use, storage, security and access of genomic data. It also sets out expectations of consent processes and distinctions between genomic data stored for research purposes (in the NGRL) and genomic data used for returning clinical findings.

6.1 The unique sensitivity of genomic data

A consistent message across all three strands is that genomic data is particularly personal and must not be used for profiling or other uses outside health. Concerns were raised about government agencies having access to genomic data for immigration or policing purposes, and about access by employers and insurance companies. This was:

- A redline for public dialogue participants;
- Articulated as an enduring commitment that should be embedded in Genomics England's constitutional framework in the inclusive communities strand;
- Highlighted by HCPs as the question patients would most need to be answered before trusting the research study or any wider roll out.

Participants in all three strands believe that genomic data is categorically different from other health data. It is permanent; it reveals information about family members who have not consented; and it cannot be changed if there is a data breach. This understanding underpinned demands for storage security, strict access controls, and strong governance that goes beyond typical health data standards.



Participant discussion of data, enablers and barriers

Participants in the inclusive communities strand raised questions about what happens to data after death, whether governance could change under future governments, and how communities could be protected from harm through misuse of genomic data. Public dialogue participants raised concern about decisions made carefully now being undone by a future government. As a result, participants call for governance structures for the research study, and for any future roll-out. They expect future-proofing of the findings from the research study (to prevent changes being made by future administrations) and secure sustainable funding for any future roll-out of genomics in healthcare. They also suggested that should funding for the research study cease a plan needs to be in place for what will happen to the data and how research study participants will be informed.

6.2 Data use and consent

Initially, across all strands, participants did not distinguish clearly between the two distinct data pathways through which genomic data could flow:

1 De-identified genomic data contributed to the NGRL for research purposes

2 Individually identified genomic findings returned to participants clinical information

Visual explanations of these separate pathways were seen as far more effective than verbal descriptions in the inclusive communities strand. Once the distinction was clear, participants were more comfortable with the research use of de-identified data but remained concerned about who could access the research database and under what conditions.

Further important questions were whether research insights from the NGRL could later become clinically actionable, and whether findings from the research database could feed back into clinical care for participants. This was live in the public dialogue where participants considered ongoing consent and the return of findings throughout the life course. In the inclusive communities strand many participants wanted to be notified of when a new research project is approved. The feasibility of this was not discussed, but these participants felt that knowing about the research could lead to more people consenting to take part in the research study. Participants' consent expectations should be specifically addressed in the research study's governance framework and communications around it.

Inclusive communities

Participants wanted consent to be a living relationship with the embedded ability to update preferences, withdraw without explaining why, and receive regular information about how data is being used. A system of ongoing consent managed actively by Genomics England was the preferred direction.

Public dialogue

Expectations from public dialogue participants included that consent would effectively balance simplicity with genuine choice, including the option to participate in research only, receive personal feedback only, or both. Digital consent via the NHS App was expected, with a human alternative with whom to discuss consent also available.

HCPs

In workshop discussions HCPs emphasised these points by confirming that informed consent requires time, support and follow-up and that it cannot be based on a single conversation. They raised the capacity implications within the NHS: if consent is to be meaningful, primary care needs adequate appointment time and staff training to support it.

6.3 Data storage and security

Data storage and data security were very potent issues raised in all the engagement strands. Participants wanted to understand exactly where data is stored (with a preference for UK-based storage), who can access it, and what technical safeguards are in place. After clarification, participants were broadly reassured about the measures in place but concerns previously mentioned about future government access and profit being pursued rather than public benefit remained. Public dialogue participants called for international collaboration to be pursued only where trust could be assured, for example where GDPR and its equivalents are in place,

and/ or only working with specific countries. Many, including those in the HCP engagement strand, wanted people to have some agency and control over their own data. Many favoured a need-to-know basis for clinical access so that only HCPs directly involved in a patient's care could access the data and then only when clinically relevant.

6.4 Sense-making workshop focused points

Data and consent generated sustained discussion in the sense-making workshop. In discussing early findings from each of the three strands, sense-making workshop participants built on points around consent design for the research study. Participants felt strongly that the research study had not yet resolved the key questions of what people joining the study are actually agreeing to. They felt that having clarity on this would be important for people's participation.

6.5 What this means

What this means for the research study

Participants believe consent design must offer genuine choices. They call for consent processes to be deliverable within realistic appointment times, and include a human alternative to digital consent. The distinction between research data and clinical findings must be explained clearly, using visual materials and community languages, at the point of consent.

What this means for Genomics England as data steward

Developing a clear, public-facing explanation of the two data pathways through which research study data could flow e.g. into research data or to be used for clinical findings is important to participants. The potential for future research or clinical re-use of the data should also be explicitly stated in governance processes and communication materials. Adopting an ongoing consent model for Genomics England to use across its research programmes is also called for by participants.

What this means for the wider ecosystem

If genomics is to be embedded in healthcare, and genomic data used for research and the return of actionable risk findings to the wider population then participants expect that the learnings from this engagement feed into future governance structures. This includes how genomic data is collected, used, de-identified and data misuse assessed across the health system.



Participants at a London public dialogue workshop.

7. Research study design, return of findings and wider-ecosystem readiness

The preceding sections of this report have addressed how participants across all three strands think and feel about genomics in healthcare, their hopes, concerns and conditions for trust. This section turns to the practical questions of delivery including what the engagement tells us about considerations for research study design, how findings should be returned and what the wider NHS needs to have in place for the research study's ambitions to be realised. Much of this is set out in preceding chapters but is summarised here for clarity on each area.

7.1 Consenting to the research study

Across all three engagement stands, participants were clear that effective consent is a foundation for the research study's success. The principles that emerged were consistent for all three strands:

- Consent documentation should be clear, concise and informative;
- Choice should be offered on whether data is being contributed for research only, to receive personal risk findings only, or both, with neither presented as the default option for the research study;
- Equally participants should be able to choose if they will receive findings on personalised medicines (PGx) only, or for condition risk findings only, or both;
- Consent should be ongoing with options to update preferences over time, withdraw from the research study, and know that their decisions would be respected;
- Consent can include digital options e.g. through the NHS App, but HCPs should also be available to discuss what consent means;
- There is an expectation that there will be time to ask questions about what is being agreed to and be signposted to further support if needed;
- Participants also asked those designing the research study to consider whether consent could enable limits to be set on data access as an additional safeguarding measure.

7.2 Return of findings

A distinction was drawn by participants between findings that are lower-stakes or easily acted on, and those that carry significant psychological weight. For the former, such as straightforward PGx information, a letter, a message through the NHS App, or a brief note on a patient record was considered acceptable. For elevated risk findings, particularly those which suggest

the meaningful probability of a serious condition, a personal conversation, not a notification, was expected. Participants are more interested in receiving the outcomes of the analysis of the genomic information, such as an adverse reaction to codeine, than genomic information.

Inclusive communities

Participants in the inclusive communities strand stressed that this personal conversation should happen quickly, so as to reduce the anxiety around receiving the risk finding. Some participants also asked for a family discussion with an HCP if the finding has implications for family members who have not consented to take part in the research study.

Public dialogue

Participants felt that returning some findings through the NHS App would be acceptable. They suggested this information should come with the details of a named person such as a GP, nurse, condition specialist or pharmacist available to speak to and expected risk information to always come with clear, personalised actions. Participants do not want to see a default to a medicalised system, believing that medicines should not always be prescribed in favour of lifestyle change advice.

HCPs

HCPs stressed the value in pre and post-test counselling as best practice, pointing to family history genetic services as the established model. However, they were candid about the capacity implications of this and expressed concern that these services currently offer support to relatively small number of patients, and they are not clear how these could be scaled up for the research study, and even less so a wider roll-out of genomic healthcare.

All participants consistently raised the tension between what they might expect in an ideal world, and what feels feasible with an overstretched healthcare system.

7.3 Sequencing research study design

Public dialogue and inclusive communities strand participants both independently reached the same conclusion on how PGx and actionable risk findings should be prioritised within the research study. Both felt that PGx could be the primary focus of the research study's initial phase. Participants think this is due to what they perceive as being the concrete and tangible benefits of PGx and the strong evidence base that underpins this. All participants could readily connect with and understand the promise of PGx.

Within the return of actionable risk findings, cardiovascular disease and dementia were seen as either ends of the spectrum for certainty and acceptability for the return of risk findings. Participants felt that conditions where the actions are established, the interventions e.g. statins or lifestyle change, are well understood, and the prospect of doing something meaningful with a risk result felt realistic are more acceptable. Participants were largely unwilling to receive risk findings for conditions where there are no clear treatment pathways, or actions that can meaningfully reduce risk. The psychological burden of knowing of this risk without any actionable response was widely seen as outweighing any benefit.

Polygenic risk scores more broadly were viewed with scepticism as participants considered that the evidence base for using them to guide individual health decisions is not yet strong enough. As a result, participants across strands felt that the research study should prioritise fewer things that could be done well, building trust in the process, rather than more things before foundations are completely solid.

7.4 Communication and awareness

Participants argued that building awareness of and confidence in the research study cannot be done through a single channel or in a single moment. Participants in the inclusive communities strand were detailed in their recommendations on raising awareness and communications:

- Materials should be layered, with short and accessible entry points that signpost to more detail for those who want and need it;
- Content should be available in community languages and delivered through channels that communities already use such as WhatsApp, YouTube, community television and trusted local radio stations;
- Trusted messengers, such as community champions, faith leaders, peer researchers and potentially community HCPs, should be enabled to convey key communications on the research study;
- Digital-only approaches were seen as likely to miss older generations and those with limited access to smartphone or reliable internet.



Participants at a London public dialogue workshop.

Some HCP participants noted that they had not known about the ambitions for genomics in healthcare set out in the NHS's 10 Year Health Plan, nor of Genomics England's role in delivering them. As a result, they felt that communication strategies should equally target HCPs as well as the general public.

Honest communications were stressed by all participants, including explicitly sharing what the research study can and cannot do. This could include sharing information on failures as well as successes. Participants also felt it was important for the research study to not over-promise, given the systemic problems that participants are aware of in terms of inequality, funding and the social determinants of health which need wider system policy solutions beyond genomics. Participants did not want excitement around a new and innovative technology to run ahead of an honest assessment of its limits.

7.5 NHS system readiness

HCPs in particular were consistent in their belief that the research study's ambitions, and any future roll-out, will only be realised if the NHS infrastructure around it is fit for purpose. This is echoed across the other two streams of engagement as well. HCPs suggested that genomic findings need to be integrated into the clinical systems that they are already using rather than adding another digital tool to an already complex system. Participants across the strands raised this point in the sense-making workshop too.

Nobody wants this project and genomics to come with yet another app that you have to have a different password and login details for. Everybody wanted it to be part of, you know, whatever system the hospitals already use, whatever system, you know, primary care already uses, rather than yet a new one to learn how to navigate.

Participant, Sense-making workshop

Participants expressed concern that digital exclusion will be exacerbated and healthcare diminished if the systems established for the research study are not well integrated into existing NHS systems.

Participants expect NHS systems to be ready if the research study is scaled up, and if the government decides in future to implement genomics in routine healthcare based on the evidence from the research study. This

includes establishing nationally standardised guidelines and clinical pathways, perhaps as part of the research study design. Participants also call for HCP training, including embedding genomic medicine in undergraduate education for medicine, nursing and pharmacy, and delivering it in a timely fashion to the existing workforce.

Readiness also includes sustainable funding. HCPs described a familiar pattern in which promising innovations are piloted, generate valuable results and are then abandoned when short-term funding ends. Many participants expressed concern that if funding for the research study ends without a roll-out of genomics in healthcare having been established, there must be clear answers about what happens to the findings and to participants' data.

7.6 What this means

What this means for the research study

The result of these deliberations across the strands of the engagement gives clear indicators for starting with PGx, whilst developing actionable risk elements of the research study slowly and with care, and only as justified by the evidence base. Participants call for the design of the return of findings pathway to guarantee access to a human conversation for any result that carries significant psychological weight. Public awareness campaigns should contain clear communications working with trusted messengers, community languages and layered materials.

What this means for Genomics England as data steward

Participants want Genomics England to be honest and transparent in communications around the research study. They expect Genomics England to work with the wider system to design the research study with an understanding of what would be required to scale it in future should the evidence from the study support this.

What this means for the wider ecosystem

For the wider ecosystem, participants believe that NHS training, infrastructure readiness, data interoperability and the development of clear support pathways for the return of findings are all prerequisites for the equitable delivery of the research study. Participants want to be reassured that all aspects of the research study that would touch the wider ecosystem are planned for and sustainably funded. They believe the research study cannot deliver on its potential for equitable delivery if the system through which the benefits flow is not ready to carry them.

8. Recommendations, redlines and trade-offs

This section synthesises recommendations from the reports [\[link\]](#) from three strands of the engagement programme, into a single set of cross-strand recommendations. These are organised by the three lenses of implications for the research study, for Genomics England as data steward, and for the wider ecosystem.

It is important to note that participants identified a genuine tension between what they called for in their deliberations, and what an overstretched NHS can currently deliver for the research study, and at scale in the case of any future roll out. Equally genomic data must never be used for immigration, policing, insurance or employment purposes. This was a consistent finding across all three strands and was independently confirmed in the sense-making workshop.

For the research study

The key implications and recommendations for the research study that emerge across the Genomics, Healthcare and You engagement programme are:

- Focus the initial phase of the research study on pharmacogenomics; develop actionable risk more cautiously and only consider PRS if the evidence base is significantly stronger;
- Design ongoing consent to offer choice on how the data will be used with the ability to update preferences over time and include a human alternative to digital consent. Including a prospective opt-out mechanism for research beyond the scope of the research study, for example for data access to the NGRL;
- Develop a return of findings pathway that always accompanies risk information with clear, personalised actions; guarantees access to a human conversation for elevated risk results; and embeds support;
- Use multi-channel, layered communication with community language materials and trusted messengers, not a one-off campaign. Include hospitals and NHS staff as active recruitment channels;
- Build diverse data participation as a design requirement for the research study, with active outreach to underrepresented communities to ensure the genomic findings being returned to them through the research study are meaningful because the scientific base is representative of all communities. Communicate explicitly to communities why their participation matters;
- Focus on actionable risk feedback first, given established treatment pathways; treat dementia-related findings with particular care given the absence of effective interventions. Consider the generational dimension with risk results for conditions with no treatment carrying particular psychological weight for younger participants;
- Build in a clear plan for the responsible wind-down of the research study if funding ends, or the political impetus for genomics in healthcare changes, including clarity on what happens to participants' data and how they will be informed;
- Deliberately reach younger participants and design trust-building communications that speak to their specific scepticism about government and institutions;

- Build a plan to communicate findings and actions related to the research study back to Genomics, Healthcare and You engagement participants including what changed, what was acted on, what was not and why.



Participants at a Newcastle public dialogue workshop

For Genomics England as data steward

Participants call for Genomics England to:

- Pursue a legal or constitutional framework prohibiting non-health use of genomic data, future proofing this principle against future changes in policy or government. This was a redline across all three strands;
- Develop and publish clear, visual explanations of the two data pathways: de-identified research study research data and the return of clinical findings. These must be distinguishable to participants at the point of consent, and the question of future clinical re-use of research insights must be addressed explicitly;
- Adopt an ongoing consent model providing participants with the ability to update preferences, withdraw, and receive regular information about how their data is being accessed and used;
- Be proactive about explaining the role of pharmaceutical companies, what access they do and do not have, what the “reading library” model means in practice, and why medicine development requires some level of private sector research access;
- Store data in the UK where possible; pursue international collaboration only where trust can be assured;
- Treat data diversity as a headline design requirement: commit publicly to building representative genomic data, acknowledge current limitations honestly in all communications, and report on progress;
- Actively communicate Genomics England’s existing track record in responsible genomic data stewardship as participants familiar with this work expressed more trust in this than those who were not;
- Put in place governance and leadership informed by a wide range of perspectives including members of the public, with ongoing accountability mechanisms and publicly reported outcomes.



Small group discussion at a Newcastle public dialogue workshop.

For the wider ecosystem

- Integrate genomics into existing NHS clinical systems with embedded, interoperable functionality;
- Develop nationally standardised guidelines and clear clinical pathways before any future roll-out beyond the research study. HCPs cited National Institute for Health and Care Excellence (NICE) guidelines as the trusted model;

- Begin role-specific training now, embedded in undergraduate education for medicine, nursing and pharmacy, with a sustained programme of upskilling for the existing workforce, timed to match clinical implementation;
- Explicitly explore the role of community pharmacy as a point of access for basic information-giving, consent conversations, and referral;
- Provide sustainable, not pilot-based, funding;
- Develop clarity on roles and responsibilities across the data flow pathways particularly between GPs, community pharmacists, and specialist genetics services;
- Address systemic access barriers (health literacy, digital exclusion, language barriers, deprivation) proactively, including through longer appointment times where needed for complex genomic conversations;
- Communicate the research study to the NHS workforce as well as to people across society. HCPs, including hospital staff, GPs, and pharmacists, should be informed and enabled to signpost patients;
- Convene cross-sector learning on inclusive engagement approaches, sharing the learnings developed in this engagement programme.

Participants at an East London workshop.



9. Conclusions

To conclude we focus on what these findings mean for the research study and Genomics England's broader ambition to bring genomics into mainstream healthcare.

Real public goodwill, with conditions attached

The engagement has demonstrated that participants are conditionally positive about the use of genomics in preventive healthcare. Across all three strands, and confirmed in the sense-making workshop, there is genuine enthusiasm for what genomics could offer, grounded in direct experience of the challenges in the current healthcare system. Participants hope that pivoting to a preventive healthcare model will ultimately save money for the NHS and contribute to the system working more effectively. The conditions that participants set can be seen as foundations on which public trust rests:

- Data being used for health only;
- Benefits reaching all communities;
- The NHS supported to deliver the research study and any future scaled up use of genomics.

A commitment to trust building and accountability

A consistent message across the inclusive communities and public dialogue strands is that this engagement is not just a research exercise, it is the beginning of a relationship. Communities in Bradford, Birmingham and East London made clear that they are willing to engage but want to know the extent to which Genomics England acts on what it has heard. This was reinforced directly in the sense-making workshop: participants from all three strands asked, at the close, to be told what changed as a result of their participation. Participants called for the research study and Genomics England

to commit to honouring the engagement findings and report against them. Participants see Genomics England's role as data steward carrying its own obligations of transparency and accountability that run beyond the life of the research study.

What the sense-making workshop crystallised

The sense-making workshop, bringing together participants from all three strands for the first time, demonstrated that when people who had engaged through very different methods in a range of different communities heard each other's findings summarised, they were struck by how much they had in common.

I thought there would be more difference between the three groups, but actually there was lots of crossover, we agree on the basics, on the main things that matter to us.

Participant, Sense-making workshop

The convergence across strands, confirmed by participants themselves, is strong evidence that these findings reflect how people in diverse communities and HCPs in England think about genomics in healthcare.

What success would look like

Drawing all sources together, the Genomics, Healthcare and You engagement finds that effective design of the research study and Genomics England, the NHS and wider policy and research infrastructure would include:

- The research study starting with PGx and building towards actionable risk in stages as the evidence on specific conditions strengthens;
- A genomic database that reflects the diversity of England's population because that was designed in from the start of the research study;
- Findings returned through the NHS App with a guaranteed human option and embedded support;
- A constitutional commitment that data will only be used for healthcare and health research;
- Communication that is honest about limitations as well as hopes; and a research programme that closes the loop by telling participants in this engagement what has happened as a result of this process;
- A wide-spread, layered and iterative communications strategy around the research study using the messages and the channels developed through this engagement;
- An NHS and wider ecosystem which can collaborate effectively with Genomics England to ensure a properly safeguarded system with effective mechanisms for the return of findings, and appropriate support in place.

Participants recognise that this is no small endeavour. They see the tension between what they would like to see to build a trustworthy system for embedding genomics in healthcare and what is feasible. However, they remain hopeful that success is possible if the foundations are laid carefully now.

Participants engage in the tree of life activity in Bradford.



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We are grateful to the research programme and study team from Genomics England. Your expertise has been an essential guide to the process.

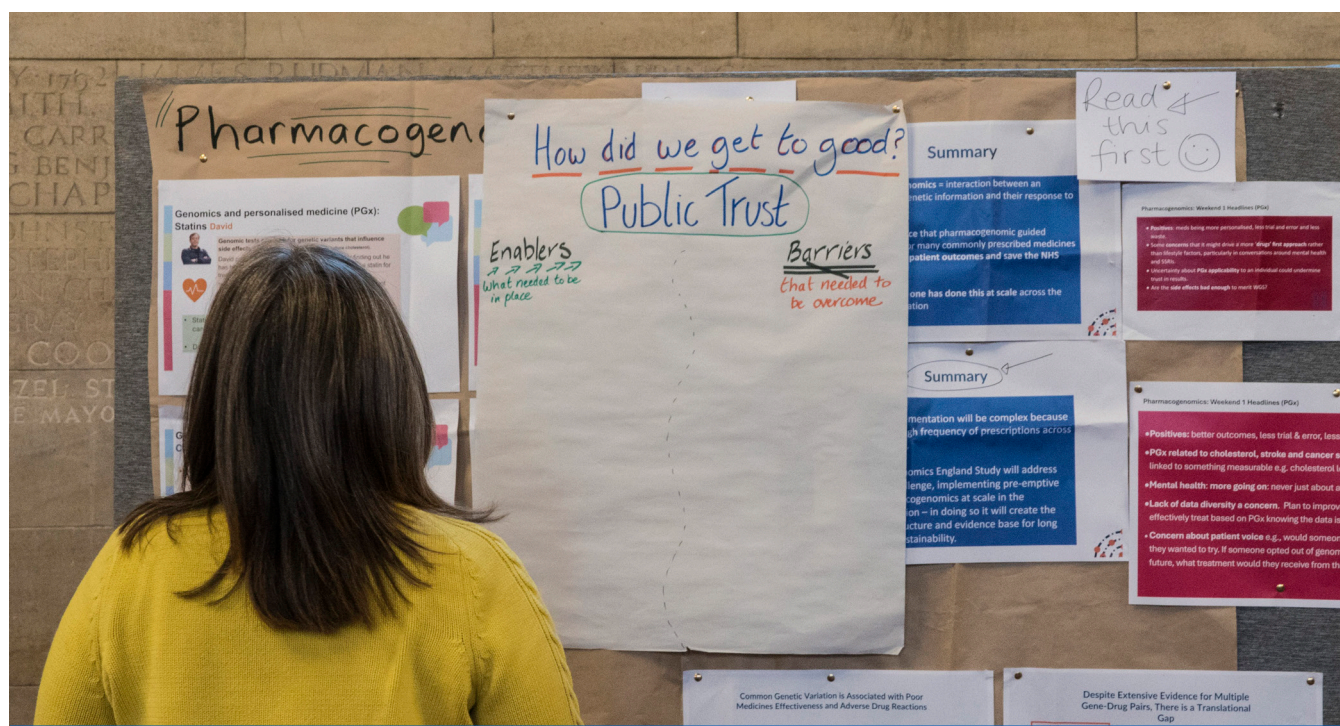
Thank you to members of the engagement programme's oversight group and the Participant Panel at Genomics England who have given impartial, informed advice, challenge and guidance on the complexities of engaging with genomics. The group worked hard to ensure the evidence, content, and stimulus materials presented to the public dialogue participants shared a range of perspectives and covered the key issues under review.

[Participant at a Newcastle public dialogue workshop.](#)

We are very grateful to all the public dialogue specialist speakers (listed in the separate appendix). They generously gave their time to ensure that public dialogue participants heard evidence and a range of views on this, at times, sensitive topic.

Thank you to our partner Paul Wyatt Films who created the powerful engagement [programme films] that accompany this report.

For detail on the oversight group members, the specialist presenters, the process designs and stimulus materials for the engagement programme go to the Technical Appendix.



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