
September 2026

Genomics, Healthcare and You

Inclusive Community Engagement Report

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Preface

This report was commissioned by Genomics England as part of their Genomics, Healthcare, and You engagement programme and was delivered by The Social Agency, People Street and the Leap.

The report explores the hopes and concerns of communities underrepresented and underserved in genomics research towards the use of genomics in healthcare. The research engaged 83 people from ethnically diverse communities in Birmingham, Bradford and East London. The report makes recommendations for the future inclusive engagement of communities, including implications for the design of the planned study into the use of genomics in adult population health and the wider governance of genomics in healthcare and research.

Executive summary

The Social Agency, The Leap, and People Street delivered the inclusive community engagement strand of the Genomics, Healthcare and You programme, commissioned by Genomics England. The programme sought to involve people underrepresented in genomics research, and engage ethnically diverse communities from Birmingham, Bradford and East London by taking an intersectional approach.

The engagement ran from October 2025 to January 2026, covering a scoping phase, interviews, and culminating in three area-based workshops. A further six follow-up interviews were conducted in February 2026. In total, 83 people participated, with 36 identifying as disabled or having a long term health condition.

The Project Team adopted a place-based, community-led approach, working through trusted local networks rather than recruitment agencies. Methods were tailored to each community, conducting sessions in mother tongue where needed, and co-designing workshop activities with participants throughout.

Key Findings

1. Hopes and concerns about genomics

Participants broadly welcomed the two main applications of genomics in population-level healthcare: personalised prescribing and early prediction of actionable health risks. Many participants shared direct personal experiences of medication side effects or the prevalence of conditions within their communities that made these benefits feel tangible and meaningful. Protecting family health and future generations was a stronger motivator for participation than individual benefit.

However, enthusiasm was conditional. Participants were concerned that the predictive power of genomics was being overstated. When discussing return of findings in personal terms, participants frequently conflated being at elevated risk of a health condition with diagnosis, a pattern with significant implications for how findings are communicated and what psychological support is provided. Views on whether to receive risk information varied, with some participants preferring not to know about conditions with few actionable treatments.

Across all groups, there was frustration that existing medicines and genomic risk models have been developed primarily using data from white European populations. Black African participants in particular felt excluded from the design of genomic research and called for meaningful representation throughout the study.

2. Trust and data security

Data security generated the most sustained concern. Participants initially misunderstood the relationship between de-identified data held in the National Genomic Research Library (NGRL) and the return of clinical findings, seeing both datasets as potentially linked and vulnerable to misuse. Visual illustrations of separate data pathways were far more effective than verbal explanations in addressing this.

Even after clarification, participants worried about future government access to genomic data, commercial exploitation, and discrimination on grounds of ethnicity, immigration status, or employment. These concerns were not abstract: they were grounded in direct experiences of institutional racism and mistrust of healthcare, research and government institutions. Participants wanted Genomics England to embed constitutional safeguards, not just procedural assurances, against non-health use of genomic data.

To build trust, participants value honesty over reassurance. They explicitly preferred frank acknowledgement of data security limits, predictive uncertainty, and gaps in existing genomic databases to overpromising and underdelivering.

3. Histories, harms and implications for genomics

Participants described widespread experiences of discrimination in healthcare, including feeling dismissed, unheard, or stereotyped by clinicians which directly shaped their scepticism about the study. For African and African Caribbean participants in Birmingham and East London, this mistrust ran particularly deep. The Birmingham workshop opened with a structured 'Listening and Sharing' session, chaired by a trusted community leader, to give Genomics England the opportunity to hear these experiences firsthand before any discussion of the study design.

Participants raised concerns about genomics reinforcing existing stigmas – around disability, disorders associated with first cousin marriages, and mental health – and about genomic information being used to discriminate in employment or harm immigration outcomes. For some, these concerns extended to fears about eugenics.

4. Information and access needs

Participants had a good intuitive grasp of genomics and could understand risk; but struggled with clinical terminology and were more likely to treat risk as diagnosis when thinking about personal impact. Visual and metaphorical explanations, including the Tree of Life exercise and Lego bricks to illustrate multi-factorial risk, were consistently more effective than written or verbal information.

For raising awareness of the study, participants recommended layered, multi-channel communication: short accessible materials pointing to more detailed information, community language content (including WhatsApp, YouTube and community TV), and trusted messengers – particularly GPs, community champions, faith leaders, and peer researchers. Digital-only approaches were seen as likely to miss older generations.

On the return of findings, participants clearly differentiated between benign findings (where feedback would be acceptable by letter or text) and elevated risk findings (requiring a personal conversation with a knowledgeable clinician). Participants said three to six months was the maximum acceptable wait time for a follow-up discussion with a clinician. Receiving detailed result information by letter was firmly rejected. The option for clinical sessions with participants' family members was also requested, given that genomic findings can affect the whole family unit.

5. Consent, lifecourse and responsibility

Participants viewed consent as an ongoing relationship rather than a one-off event. Some wanted to be notified of every request to access their data for a research project though they had not considered the operational implications of this. A workable ongoing consent model that is actively

managed by Genomics England, rather than placing the burden on participants, was the preferred direction. This model could periodically remind participants of what they have consented to, how their data is currently used and likely to be used in the future, and remind them that they can withdraw from the study.

Intergenerational considerations, including what happens to data after death, how governance could change under future governments, and how communities can be protected over time, were prominent. Religious dimensions (for example, that our health is determined by God's will) were acknowledged but seen as a minor barrier, provided Imams and religious leaders are engaged in advance.

Recommendations

To help promote the future inclusive engagement of communities in the study, the following is recommended.

1. Engagement practice:

- Invest in place-based, community-led outreach via trusted local networks;
- Embed mother-tongue facilitation as standard;
- Adopt an approach that builds knowledge with communities using plain language, visual tools, and culturally relevant framing;
- Build explicit feedback loops demonstrating how community input shapes the study.

2. Study design:

- Develop a workable ongoing consent model in consultation with communities;
- Produce clear visual materials on data flows, governance, and safeguards;
- Treat data diversity as a design requirement, not an afterthought.

3. Long term data governance:

- Explore a foundational and enduring constitutional commitment, not simply a policy commitment, to prohibiting non-health access to the genomic data held in the NGRL, including by governments;
- Develop clear, layered explanations of the technical safeguards in place.

4. Healthcare system:

- Provide clarity on how return of findings will be resourced at scale, given pressure on primary care;
- Ensure psychological support is embedded in the return of elevated risk findings;
- Avoid overstating what genomic data can currently predict, particularly given lack of diversity in existing databases.

Implications

The engagement demonstrates that communities underrepresented in genomics research have substantive, thoughtful views about its potential and its risks. Communities are willing to participate and are often motivated by family and community benefit as much as personal health – but only if the study design, governance, and communication earn their trust over time.

The findings have implications beyond this programme. Several large UK health research studies face similar challenges around participant diversity. There is value in Genomics England convening cross-sector learning on inclusive engagement approaches, particularly regarding ongoing consent, community-led recruitment, and culturally sensitive communication of genomic risks.

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): is 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. Inclusive engagement inclusive community engagement actively works to reach and involve people who wouldn’t otherwise take part. It goes beyond equal access (the same invitation to everyone) to address the practical, cultural and structural barriers that keep particular groups out of being involved, such as timing, location, language, format, trust, or a history of being asked but not listened to. This involved targeted outreach, working with trusted intermediaries, offering different ways to take part, and adapting methods so that people who are seldom heard, are genuinely able to contribute.

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

1. Context of the study and inclusive engagement programme

The Social Agency, People Street and The Leap (the Project Team) delivered the inclusive engagement strand of the Genomics, Healthcare and You programme. This strand was organised into an initial 'scoping phase' from October to December 2025, followed by community workshops in January 2026.

The scoping phase was designed to connect and engage communities underrepresented in genomics research in Bradford, East London and Birmingham, and build the mutual understanding and trust required for workshop discussions on the potential use of genomics in pre-emptive healthcare.

This report summarises the approach and findings of the inclusive community engagement strand. It documents the:

- Context of the study and engagement programme
- Principles guiding the community engagement design
- Methods to engage communities
- Cross-area themes emerging from the engagement
- Recommendations to strengthen ongoing engagement in the study, both for Genomics England and other healthcare organisations.

This chapter describes the context in which the programme was developed. Genomics England's role as the commissioner of this significant programme of engagement is explained. The work done by the partners in the engagement programme is introduced.



A group of participants taken at a Birmingham workshop.

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 which 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 to be offered as standard, caring for 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. Whole genome sequencing is then used to seek an explanation for the underlying genetic variation(s) that could explain those symptoms, or that could help determine the best treatment pathways.

Genomics England has now been funded by government to explore the potential for an adult population genomic research programme (the study) 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.



Small group discussion at the East London workshop.

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). In addition to the inclusive communities strand, which is the subject of this report, engagement with healthcare professionals (HCPs) was led by RAND Europe, and the public dialogue programme by HVM. Each of the engagement strands are reported on separately by the lead partner. A final report sets out the overarching findings and common themes from the full programme.

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 was established to advise and challenge the process which was also guided 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): likely to be the primary focus of the potential future adult population research programme. 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 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.

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 organisational strategy is shaped by diverse perspectives and public expectations.

In advance of the engagement programme, Genomics England commissioned a literature review to explore what was known and evidence gaps concerning public and healthcare professionals' views on population level genomic testing.

The review highlighted the need to develop inclusive recruitment strategies that reach underserved groups and highlighted the following design challenge:

- How can we actively and meaningfully engage these communities to understand their specific needs, attitudes, cultural considerations, and barriers to participation, ensuring the study is truly equitable and inclusive by design?

The Project Team developed participant-led, in-community workshops tailored to different groups to help address these issues. Principles guiding the engagement are explored next.

Small group discussion at the East London workshop.



2. Principles guiding the community engagement design

Genomics England commissioned the inclusive community engagement strand of the Genomics, Healthcare and You programme to understand the particular hopes, concerns and questions of people from communities underrepresented in genomic research. It aimed to involve people:

- From specific ethnic minority communities, focused on the five largest ethnic minorities from the 2021 UK Census data – namely people from Black African, Black Caribbean, Indian, Pakistani and Bangladeshi ethnicities;
 - Who are unable to participate in deliberative processes because of their own health or care needs or the health of people they care for.
- 
- from UK Census data were broad (e.g. Black African) and risk missing important differences across groups in terms of culture and histories, and experiences institutional mistrust and discrimination;
 - Build trust and ensure the engagement was not extractive – as communities can feel targeted by genomic research and may be suspicious of Genomics England's motives to engage with them;
 - Start with where communities are – and the importance of participants framing the debate and context to enable a meaningful discussion of the return genomics findings;
 - Develop a process to account for cultural differences and scientific literacy – given that communities will understand, interpret and discuss terms such as genomics and DNA in culturally specific ways.

Small group discussion at the East London workshop.

The Project Team highlighted several considerations for the design of this engagement strand in this context, including a need to:

- Account for different cultures, practices and lived experiences around healthcare – and that the ethnicity categories identified

To address these considerations, the Project Team took a place-based and community-led approach and explored the intersection of ethnicity with other health inequalities.

Specifically, the Project Team located the research in three ethnically diverse areas: Birmingham, Bradford and East London, and worked through existing networks to engage different community groups.

The Project Team recognised that communities are not homogenous. Experiences of healthcare, research and health data are shaped by intersecting factors including migration experiences, language confidence, disability and long-term health conditions, digital exclusion, gender, caring roles, and socioeconomic insecurity. The Project Team used this intersectional lens to understand how barriers compound and how trust is built or undermined.

While sharing common elements, methods to engage communities were tailored to and differed in each area, to account for local contexts, community histories, levels of familiarity with genomics, and practical barriers to participation.

Specifically, the Project Team:

- Held workshops in familiar community settings;
- Used methods which enabled participants to engage with the subject matter in ways that aligned with different cultural practices and oral traditions;
- Conducted sessions in mother tongue, as needed, to support participation;
- Adopted a flexible design, which changed in response to emerging community concerns;
- Adopted an iterative approach, revisiting themes across sessions, and providing opportunities for reflection, clarification, and deeper exploration.

Pre-workshop briefings were offered to ensure participants felt confident, informed, and prepared to contribute. This preparatory step helped to reduce power imbalances and supported participants to take part as active contributors to shaping the discussion rather than passive respondents.

The Project Team reported back to communities after each meeting, demonstrating how insights were being captured and carried forward. This approach sought to counter perceptions of research as extractive and to build accountability between the engagement programme and the communities contributing to it.

Community-led engagement methods have a long history in community planning, development and healthcare but are less commonly used to engage people in discussions about emerging areas of science and technology – where deliberative public engagement and social research methods dominate.



A participant and a Genomics England representative at the East London workshop.

Overall, the Project team's community led method differed from a more traditional deliberative social research approaches in several important ways, summarised in Table 1.

Table 1: Methodological differences between social research approaches and the community led approach adopted for the engagement

	Social research	Community led
Sample	Specific demographic quotas recruited	Intersectional approach, but not purposively recruited to quota
Recruitment	Via a qualitative research recruitment agency, using databases, adverts and in person recruitment	Via trusted community networks, using peer-led recruitment
Discussion guide	Standardised across groups, primarily tailored to client research questions	Different across groups, primarily tailored to different community contexts and needs
Workshop materials	Greater focus on written information or presentations, can include technical language	Greater focus on oral and visual information, complex ideas explained through metaphors and learning by doing, or play
Analysis	Greater focus on the systematic analysis of transcripts to a common code frame	Greater focus on brainstorming, feedback and community validation of findings

The strengths and limitations of the specific methods used in the engagement are shown in the Technical Appendix which accompanies the suite of reports from Genomics, Healthcare and You.

3. Methods to engage communities

3.1 Recruitment

The Project Team’s recruitment approach focused on community outreach, working with trusted local people to recruit participants through local networks. The Project Team used this approach to involve participants often missed by traditional recruitment practices (for example, via qualitative recruitment agency or via the voluntary sector).

The Leap and recruitment in Bradford

The Leap led recruitment in Bradford. The Leap is an arts-based organisation that works directly with local communities, providing support for them to build their confidence, knowledge, and skills to support social change. The Leap’s outreach focused on engaging community leaders (such as faith group leaders) from Bangladeshi, Pakistani, Nigerian and Somali communities.

Community leaders had a wide range of questions about the engagement activity, including its purpose, the motivations of Genomics England to undertake the engagement, how findings would be used, and the longer-term benefits to the community. The Leap held meetings with community leaders over several weeks to explain the engagement’s purpose, process, and practice. The Leap’s existing relationship with communities was an important aspect of communities agreeing to take part.



Participants at the London workshop.



Participants at the Birmingham workshop.

People Street and recruitment in Birmingham and East London

People Street led recruitment in Birmingham and East London. People Street is an organisation set up to connect excluded voices with decision-makers to create fairer policies, services, and opportunities. The recruitment was led by People Street’s ‘Outreach Leaders’ – their network of over 150 people representative of a wide range of communities. In East London, People Street engaged communities from Bangladesh, India, Somali, Sierra Leone, and Uganda. In Birmingham, People Street engaged people from Afro-Caribbean and Nigerian communities.

Characteristics of participants across all areas

Overall, 83 people took part in the workshops which comprised the scoping phase of the inclusive community engagement. Table 2 summarises the main characteristics of participants. Additional sample details and differences in the demographic information collected across groups are provided in the technical appendix published as a separate document.

Table 2: Characteristic of participants in the inclusive community engagement

Characteristic	Number of people engaged (n=83)
Area	Bradford: 39 Birmingham: 22 London: 22
Gender	Female: 49 Male: 34
Age group	16–24: 9 25–34: 26 35–44: 23 45–54: 16 55+: 9
Ethnicity	Bangladeshi 20 Indian: 13 Pakistani: 14 Black African*: 21 Black Caribbean: 15
Disabled or long-term health condition	36

*Black African communities included people from Nigeria, Somalia, Uganda, Sierra Leone, Zimbabwe

3.2 Community engagement design

Overview of approach

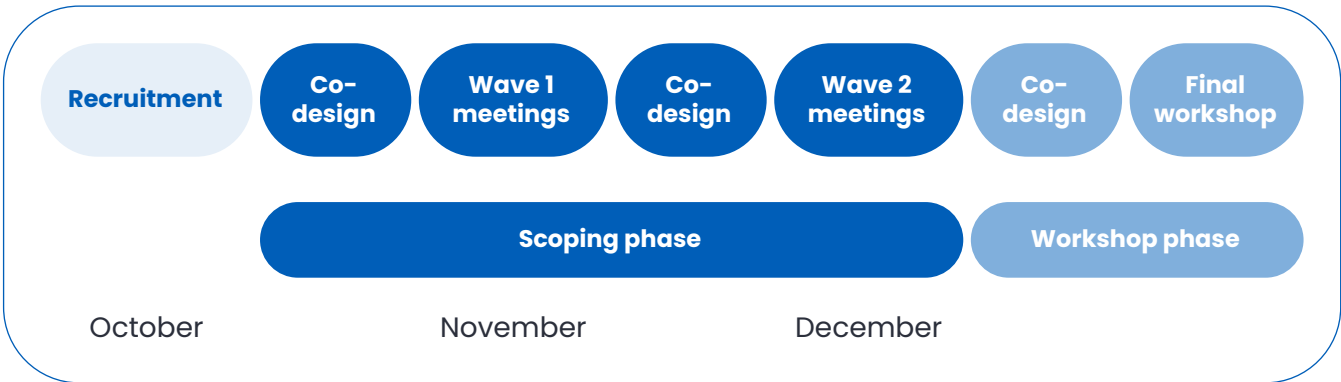
The community engagement involved a scoping phase and workshop phase and took place between October 2025 and January 2026 (see Figure 1).

The scoping phase explored participants lived experience and cultural context, their

framing and understanding of genomics and initial thoughts about the study.

Separate meetings, each focused on a specific community, were held with participants during the scoping phase to create a space where different cultures, histories, and experiences of discrimination and institutional mistrust could be more openly discussed. In this context, Bangladeshi women were convened as a separate group,

Figure 1: Community engagement design



to enable a more open conversation than may have been achieved in a mixed gender group. As needed, several meetings were conducted in mother tongue, and it was common in all meetings to switch between English and other languages. During the scoping stage, meetings were predominantly conducted as small group discussions, though interviews were also undertaken for participants who were unable to attend a face-to-face discussion. Participants met twice during the scoping phase and had opportunities to help set the agenda and shape the activities in each meeting. Before each meeting, participants were briefed to help build confidence and support their participation, particularly for people with low literacy and/or limited English.

The workshop phase built on these initial discussions and explored the study design and potential applications of genomics in detail. Each workshop involved approximately 20 people and brought all communities together for an in-person meeting in each area. Members of the Genomics England team attended the workshops, and the sessions were conducted in English.

As noted earlier, the Project Team developed an approach that was tailored to each area and co-created with participants. Consequently, while following a similar process, the precise community engagement activities differed across Birmingham, Bradford and East London. In the following sections, common elements of the design are described, together with examples of different methods employed. A separate Technical Appendix provides details on the design for each area.

3.3 Scoping phase design

The scoping phase meetings were designed to start where people are, providing the space and time to discuss their lived experience and social context, and build the trust and understanding required for deeper conversation about the use of genomics in healthcare.

For the first set of meetings, conversations initially centered on getting to know participants, understanding their day-to-day lives, and how they felt about their health and healthcare. Additionally, participants discussed:

- What do genes and DNA mean to them and their community?
- Initial thoughts on the potential benefits and concerns of using genomic data in healthcare;
- Awareness of and questions about Genomics England.

Given that genes and DNA were relatively abstract concepts, different exercises were undertaken to help participants engage with the subject and link it to their lives. These exercises were designed to engage different learning styles, placing less emphasis on written materials in recognition of the lower literacy levels of some participants, and greater focus on creation and play. Exercises are illustrated in figure 2 and included:

- Drawing and design exercises to consider what makes individuals unique (biologically and socially);
- Projective exercises, including collage and word associations, to understand what participants associated with terms such as DNA or genome;
- A Tree of Life exercise, which enabled participants to reflect on the relationship between their past, present and future, and articulate hopes and concerns around the use of genomics in healthcare. In considering The Tree of Life, participants explored:
 - The roots: beliefs systems and ancestry;
 - The trunk and branches: lived experiences of accessing the UK health system;
 - The leaves: hopes and fears relating to genomics in healthcare.



At the end of the first session, participants were asked to share what they wanted to know more about concerning the use of their genomic data in healthcare, who they would like to hear from and in what format.

After the meetings, the Project Team produced a headline report for participants that highlighted key points raised by each community and invited further feedback from participants on questions and topics for the next meeting.

The second set of meetings involved the opportunity for participants to learn more about the study and discuss the implications of collecting and using their genomic information for healthcare, including the return of findings. In response to a specific request in Bradford, this included hearing answers directly from the Genomics England team to questions raised by participants, including how Genomics England is funded, how genomic data is stored by them and who will have access to it. Answers were provided by Genomics England via a pre-recorded video.

Additionally, questions co-designed by participants, using language which resonated with them, included:

- What are your thoughts on DNA/ gene testing becoming part of NHS healthcare for adults?
- Are there certain situations when you would like to receive information about your DNA/genes?
- Imagine the NHS had your 'gene data', how would you like to receive your DNA information?
- How do you feel about your DNA information being stored throughout your lifetime, with the possibility of learning more as research advances?
- Can you tell me why you feel this way? (In relation to the answer to question above)
- What are your hopes for, and concerns about DNA/gene testing in healthcare?

During the second meeting, greater focus was placed on group discussions (vs creative activities), allowing participants space to talk about sensitive issues including racism, the community stigma associated with genetics (for example, related to first cousin marriage or the use of DNA for paternity testing), and concerns around physical and mental health.

After the second wave of meetings, the Project Team also produced a headline report for participants that summarised the views shared by each community. The Project Team also canvassed interest in attending the main workshop, and participants were invited to sign up if they wished.

3.4 Workshops

The community engagement process culminated in a day-long workshop held in late January 2026 in Birmingham, Bradford and East London (see figure 3). The workshops were designed to explore the study in greater detail and discuss participants' views on the return of genomic findings to help improve medicine prescribing and feedback on actionable risk. Workshops also involved creative exercises to help co-design communication activities to help engage communities in the study. In advance of the workshop, briefing calls were held with participants to help prepare them.

As with the scoping phase, the workshop design differed by area and was tailored to community needs. The following structure was broadly followed in each area:

- A session to welcome and energise participants;



A participant at the Birmingham workshop.

- An opportunity to meet the Genomics England team and learn more about the study;
- Discussions on:
 - How data is stored and accessed in the study;
 - The lack of diversity of existing genomic databases and risk models
 - Actionable risk
- Three small group discussions, with parallel sessions on the following:
- How to improve the diversity of Genomics England's database, given 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;
- How to promote participation in the study;
- How to communicate about the elevated risk of health conditions, and a co-design exercise on the return of actionable risk findings;
- How to improve participants' experience of medication prescribing, and a co-design process on the use of pharmacogenomics.
- Group sharing, reflections and feedback.

Several activities were used to engage participants in the subject matter. This included using:

- Hand drawn flipcharts, rather than presenting slides, to provide details on the day and the study;
- Lego bricks to illustrate actionable risk and risk thresholds;
- Pen portraits and case studies to bring applications of genomics in healthcare to life;
- Creative activities for the co-design element such as drawing, writing, video.

The Birmingham workshop differed from the Bradford and East London workshops in two ways.

First, due to the community's deep mistrust of public services – related to past harms and experiences – the Birmingham workshop started with a 'Listening and Sharing' session. The session was chaired by Sandra Griffiths, a trusted community leader, and enabled Genomics England to hear firsthand about these experiences and reflect on the purpose and hopes for the study in this context.

Second, participants explored the main themes of the workshop: lack of diversity in genomic data, data security, return of findings on actionable risk, improving prescribing, using a methodology called The Good Ancestor.



Participants engage in the tree of life activity in East London.

The Good Ancestor methodology involves a six-stage structured process where participants consider their past, present and future – and through this could consider what it means to be good ancestors in the context of genomics. The method was selected to empower communities and ensure the conversation could move beyond current, relatively negative experiences of healthcare and embrace hopes for a better future. Further details on the method can be found in the Technical Appendix.

3.5 Interviews with participants

As noted earlier, interviews were also conducted with participants who could not attend the meetings during the scoping stage or the final workshop. Interviews held during the scoping stage were conducted via telephone and followed a discussion structure that mirrored themes from the main meeting. In total 44 interviews were conducted during the scoping stage, during November and December 2025.

An additional 6 interviews were completed after the workshops. These interviews were focused on family members of participants in the main workshop and were used as an opportunity to sense-check workshop findings and further explore emergent issues, particularly how people feel about discussing health matters within the family, including the familial implications of genomic findings. These interviews took place in February 2026.

3.5 Analysis

The Project Team collected field notes during the scoping stage meetings. These notes were written into an analysis proforma, the structure of which mirrored the discussion guide. Findings were shared and validated with participants after each meeting.

For the Birmingham and East London workshops, notetakers were assigned to each group to record discussions. For the Bradford workshop, a mixture of moderator notes and audio recordings were used to capture findings. A topline analysis was conducted separately for each workshop. The Project Team then developed a thematic framework, based on the workshop topline analysis and findings from the scoping stage. Data across the entire community engagement process was re-analysed and redrafted within this thematic framework.

Findings from the engagement are explored in the next section.

Main findings

4. Main findings

The following section provides an integrated, thematic analysis of findings from the community engagement activities in Birmingham, Bradford and East London.

The findings cover activities from the scoping stage and the final workshop. Unless otherwise stated, findings were consistent across communities. Findings are structured by five themes:

- Hopes and concerns about genomics;
- Trust and data security in genomics;
- Histories and harms;
- Information and access needs;
- Consent, lifecourse and responsibilities.

4.1 Hopes and concerns about genomics

Personalised prescribing and reduced side effects

The potential use of genomics to help understand whether medicines would be effective or cause an adverse reaction was generally welcomed across communities. Several participants shared detailed personal experiences of medication problems that made the case concrete and compelling.

One participant described being on thyroxine for life but experiencing side effects when she took it. Others listed blood pressure medication, statins, and amlodipine, all carrying ongoing side effects.

One participant had a life-threatening reaction to codeine after a miscarriage, where she stopped breathing. She now wears a red wristband in the hospital to flag the allergy.

When I was expecting my second child... I had a miscarriage, and then I was given a painkiller and I... I stopped breathing. There were about 10 doctors around me.

So, I've got now a red band. Whenever I go in the hospital, it says on my wristband that I have a bad reaction to codeine... So, the purpose of taking your DNA... if they can make medication that does its job but has the least side effects, or no side effects, then that would be great.

Participant, Bradford

Participants reflected that they could not know what medications they might have an adverse reaction to until it happened, underlining the preventive value of testing. The appeal was direct: if testing could identify a medication with fewer side effects that does the same job, participants said they would be “more than happy.”

In addition to adverse reactions, it was common for participants to say they took medications that did not work for them. This was not only a concern for treating ill health; it also undermined confidence in the healthcare system more generally.

I am taking anti-depressants and they are not working. I am sleepy all the time. Tried another one, still doesn't work, feeling the same. Then I stopped taking them... This has affected my trust in the GP.

Participant, East London

Participants described a complex way in which they treated different illnesses, including using a mixture of “herbal remedies” as well as “normal medicine”. Certain participants expressed a belief that normal medicines were far more likely to have side effects, and that herbal remedies were effective but “just slower”. Given this range of experiences, participants said their adherence to prescribed medication was mixed.

Related to the acceptability of genomic testing for improved prescribing was how it might be employed, and the extent to which this empowered communities. For example, empowerment could be by raising health literacy and providing people with information about their health that they could act on. As discussed later, participants had mixed (and often poor) experiences with GPs when being prescribed medications – describing feeling unheard and lacking agency. There is an opportunity for the study to provide genomic information to help change these dynamics for the better.

I was told what to take by my GP and had very little choice. [Pharmacogenomics] is a good thing as it could give us more agency, but it will need work beforehand to help tackle misunderstandings.

Participant, East London

In this context, while views were broadly positive overall, the Pakistani community in Bradford expressed concerns about the application of personalised medication. The community felt it could reinforce and exacerbate existing power structures and practices, with GPs relying on prescribing medicines as quick fixes to how people were feeling, rather than properly listening to patients' concerns.

Early diagnosis and prevention

The potential use of genomic testing to enable early identification of developing a risk of a health condition was also generally positively received across communities, especially where it enabled individuals to take preventive action. However, the relative complexity of this application of genomics prompted a wider range of concerns amongst participants, relative to the discussion on improved prescribing and PGx.

In terms of hopes, participants identified a wide range of personal, family and community benefits related to understanding an elevated risk of a condition. For example, Bangladeshi women were broadly in favour of knowing about elevated risk, primarily so they could make lifestyle changes or seek screening and early treatment.

Protecting the family and better knowledge of the risk of hereditary conditions was particularly motivating. Several participants said they were broadly aware of health conditions in their family but had put this knowledge "out of mind". They felt a genomic test would make them more aware of risks of conditions and encourage action.

Like, diabetes is in my family; heart disease is in my family. We know it's in our family. But we're not... we're not prepared for it. Having samples of DNA means you know your kids are a carrier, your grandchildren are a carrier... it makes you more aware of it.

Participant, Bradford

In cases where there may be fewer options to make lifestyle changes to manage risk, such as an elevated risk of dementia, participants said that getting genomic feedback could help people prepare psychologically and plan for their families.

With cancer, we presume you might not live for very long. With dementia, there are more considerations like power of attorney, where the person lives and what support they need. We would want to know about dementia to plan support and care appropriately.

Participant, East London

However, a desire to get feedback was by no means universal and, while less common, several participants said they would rather not know about conditions where there are few effective actions or treatments available.

Knowing that I've got an incurable illness would just make me worry. I'd prefer not to know.

Participant, Bradford

I don't want to know about the things I can't do something about...I want to know about the risks that are preventable.

Participant, East London

Is mental health going to get worse or better if people know? ... It could change my happy go lucky attitude... I could live a life full of dread.

Participant, East London

The broad consensus was that the return of findings on actionable risk would always be a matter of personal preference, and that these preferences could change over time. While not explored in depth, participants discussed the conditions under which consent for returning findings could be granted. As consent needed to be gained prospectively, participants believed it would be impractical to have a long list of conditions to consent to.

Rather, participants wanted illustrative scenarios of example conditions to consider – for example, in terms of a condition's seriousness, potential onset (near versus longer term), the extent to which the risk was personally actionable and/or could be managed effectively within an existing healthcare pathway. These broad areas of consent could then be used to make specific decisions about whether to return findings regarding actionable risk.

Underpinning the above was participants' belief in the predictive power of genomics. Receiving findings from a genomic risk score was seen to be more definitive than having a family history of a condition. Participants initially gave less thought to the fact that results from genomic testing may have significant uncertainty. This was compounded by participants conflating having an elevated risk of a condition with diagnosis.

It should be noted that, in general, participants had a good understanding of the concept of having an elevated risk of a condition: describing it as "a greater likelihood compared to the average person". However, several participants thought that having a higher risk would mean they would "definitely develop the condition". Moreover, when talking about case studies concerning the feedback on actionable risk, it was common for participants to treat the return of findings as though it were a diagnosis.

An important finding is that when discussing risk in the abstract and impersonally, participants generally understood it was different from diagnosis. When discussing risk in the context of return of findings, and thinking about the impact on them personally, participants tended to imagine themselves developing the condition and discussed the case studies as akin to a diagnosis. This has implications for how participants may react to communications on actionable risk and the associated support they may need (such as a genetic counsellor).



Small group discussion at the East London workshop.

Representation in medical research

Across all groups, there was a belief that current medications (and broader healthcare systems) have been developed primarily for white populations and may not work as effectively for other ethnic groups.

Medicine is always developed for White people first. This sounds like the first time other people are being included.

Participant, East London

In a related point, Bangladeshi women in Bradford drew a direct line between underrepresentation in drug trials and their community's high rates of diabetes, heart disease, and medication side effects.

As participants learned more about community underrepresentation in genomic databases, their belief that genomics was highly predictive lessened over the course of the engagement.

Black African participants expressed particular frustration and disappointment that, when considering polygenic risk, existing genomic risk models are less accurate for people who are not from non-white European ancestries, describing this as reinforcing a sense that health systems were “not designed with them in mind”. They requested that Genomics England be more deliberate in engaging with stakeholders and creating opportunities for Black Africans to participate in the study design and delivery.

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

Participant, Birmingham

Despite scepticism about whether the healthcare system would ever really work in their favour, participation in the study was seen as important precisely because research databases needed to include their community's genomic data.

One participant made a particularly compelling point: her mother is a small, slim woman who eats a very healthy diet of fish and vegetables, yet she has diabetes. The participant wanted genomic research to both investigate why South Asian communities are disproportionately affected by conditions like diabetes and heart disease and help develop new treatments for their communities.

Family and community health

The family was identified as a primary motivator for participation in the study. Participants who were relatively indifferent about their own health became significantly more engaged when the conversation turned to what genomic findings might mean for their children.

I want to do them for my future family. I am not doing it for me but for our collective future and children. Medicine is really important. I give my data for a lot of other things anyway.

Participant, East London

Participants shared many personal experiences and stories concerning the importance of better knowledge about inherited conditions. One described being a haemoglobinopathy carrier and needing her son to understand his carrier status for future family planning. Another described discovering that three of her children had Factor VII deficiency, which could have been life-threatening in an accident if undetected. A third participant, whose best friend had died of ovarian cancer, described how the friend's

sisters desperately wanted more regular genomic testing to understand their own risk.

Beyond the family, the importance of sharing genomic information for community benefit was also frequently mentioned by participants. Altruism, rather than self-interest, was a key motivator to take part in the study. Community-level participation was seen to have a range of benefits, from understanding the prevalence of different conditions affecting communities, such as diabetes and heart disease, to promoting health literacy, which was particularly important given community-wide health implications of findings. Improved health literacy included better knowledge of:

- How genomics could be used in healthcare;
- How pharmacogenomics (PGx) can support prescribing decisions – for example, in terms of helping to identify potential adverse drug reactions, drug effectiveness and correct doses;
- The scope and limitations of genomics in predicting an elevated risk of a condition.

The study could also enable community discussions on taboo issues such as ill health resulting from first cousin marriages or mental ill health and depression.

There is a lot of stigma attached to taking anti-depressants within the Somali community. People are particularly concerned about becoming addicted and being dependent on them for life... It's not uncommon for parents to reduce their children's dosages of antidepressants without them knowing... If people understood that PGx is more personalised to you, they are more likely to take the full course of medication.

Participant, East London

4.2 Trust and data security in genomics

Data security and misuse as the dominant concern

The security of personal genomic data collected and stored as part of the study, and the potential for data misuse was a prominent concern, generating the most sustained and emotionally engaged discussion. Views evolved over the workshop sessions.

Initially, participants expressed concerns that their genomic information and personal information would be shared without consent, either because an interested party simply chose to access it, or because of a data leak, or human error.

Participants also raised fears about ethnicity-based identification and deportation, and employment discrimination based on genetic predispositions (these concerns were particularly pronounced for Pakistani and Nigerian participants).

Only time we have heard about DNA is in connection to moving to the UK. Understanding what Genomics England is trying to do differently is very important to build trust.

Participant, East London

In this context, there was an initial widespread misunderstanding that the National Genomic Research Library (NGRL) of genomic and clinical information looked after by Genomics England would hold a database that combined a person's genomic data with personally identifiable information, such as their name and contact details. To clarify this misconception, the NGRL was explained verbally during discussions, and (for groups in Bradford) also via a video from the Genomics England team. However, participants often did not fully understand these initial explanations. This misunderstanding was due to the different purposes of the study – the storage of deidentified data in the NGRL for research purposes, and the return of findings to individuals for clinical purposes. The links

between these two datasets were unclear to participants and seen as potentially vulnerable to data leaks.

Consequently, one of the most effective ways of communicating about data security was pictorially rather than verbally: with images clearly showing the separate paths for NGRL data, and the return of study findings.

Upon learning more about the NGRL and how Genomics England had strict controls around data security and access, participants still expressed a wide range of concerns, including:

- Who would be able to access the data;
- How consent for use of their genomic and health information would be governed both for their own healthcare and research;
- That participants' views may change over time and whether a model of ongoing consent would be needed in practice;
- Whether their genomic information could be used for purposes they would not agree with or to boost the profits of unethical companies;
- What would happen to their genomic information after their death.

A fairly widespread view was that data would eventually be misused by either government or companies. Regarding the government, there was significant unease around the current political climate and rise of racism and Islamophobia. Consequently, participants worried that population-level genomic data could be used to stigmatise communities and about the potential danger of a change in government to one that is hostile to different ethnic communities. They wanted to know whether Genomics England has made any commitments that could be honoured over time.

Access to my information can target me and others like me. Oh, they're not white British or, you know, genetically they're inferior. They've got this medication, it's costing the NHS. Let's get rid of them!

Participant, Bradford

Is this going to be a new source of discrimination? The world is a scary place for racialized people. There are dangers of power hungry people like ICE in the US. Black people don't feel safe giving this info up.

Participant, Birmingham



A facilitator and participant in discussion at the Birmingham workshop.

With regard to companies, participants from all communities believed that profit would be the primary motivation for the pharmaceutical industry wanting to expand the use of personalised medicines. There were several consequences of this. First, was a belief that it would increase the use of drug prescribing as a quick fix for health problems. Second, there was scepticism about whether "genuine cures" would be realised if it was more profitable for companies to continue treating an illness. Third, groups expressed concerns about misuse of genomic data by companies, once their data is shared.

Commercial pressures inevitably take precedence over public good. The multinationals will commercialise it, basically make money, and try to control the masses.

Participant, Bradford

You can withdraw but how safe and far travelled has the information gone?

Participant, Birmingham

Trust in healthcare professionals and impacts on the healthcare system

Trust in healthcare professionals (HCPs) differed by area and across communities. Despite experiences of discrimination in healthcare (discussed later), trust in GPs was relatively high among the Bangladeshi women in Bradford, who saw genomic information as not fundamentally different from other sensitive health data they already share with their doctor. Bangladeshi women placed greater trust in their GPs, than in community pharmacists. Pharmacists were seen as less knowledgeable, and there was also a concern that sensitive health information was less secure in pharmacy environments.

The Pakistani community in Bradford was also broadly positive toward health professionals individually, but this was overshadowed by a view that the health system itself was “broken” and that access to GPs was very difficult. Despite this, there was acknowledgement of the fundamentally important role of HCPs to deliver the promise of genomics in healthcare.

Most people will just listen to the doctors... they won't read genetic information about whether a medicine will be good for them or not, they just want the result.

Participant, Bradford

African and African Caribbean participants generally expressed greater mistrust with doctors and the healthcare system more broadly, preferring alternative medicine or avoiding altogether. Participants in East London and Birmingham mentioned going abroad for private treatment. The combination of long wait times, short appointments and not feeling listened to in appointments made some sceptical about doctors' abilities to handle more information.

Me and the NHS are not friends.

Participant, Birmingham

Across all groups, there was a distinction between trust in individual clinicians and trust in the system. Services were described as poor and overstretched and often involved long waiting times for routine appointments.

It is a mess... appointment times are not long enough to explain properly, especially juggling language barriers and misconceptions.

Participant, East London

Participants questioned whether genomic technology would help create efficiencies or place further burden on an already struggling healthcare system. Specifically, participants described the NHS as struggling to cope with existing demands and therefore not in a position to manage new responsibilities arising from the use of genomics in healthcare.

Where will the NHS get the money from? What happens if the medicine that will work best for you is not available on the NHS? How will this fit with very short GP appointments?... Very important that this doesn't add any further delay to GP appointments and treatment.

Participant, East London

Additionally, participants worried that increased identification of disease risk would generate increased anxiety and mental health issues that the NHS was not equipped to address both in terms of capacity (few available staff) and capability (staff without the right clinical or community knowledge).

Low trust in governments

Similar to the NHS, trust in government was low across all groups. Genomics England's status as a government-linked organisation was a concern in this context. Governments were described as lacking both competence and stability to deliver on their promises and that “commitments made one day could change the next.”

There were concerns that oversight of the NGRL could be subject to future government interference, and participants were not satisfied with assurances that the government cannot access the data. For example, a significant question raised by participants was how to ensure the integrity of the programme against changing political stances or government shifts. They wanted a foundational, enduring commitment embedded in Genomics England's constitutional framework that data would never be released to the government, accompanied by plain-language explanations of the technical safeguards in place (secure data environments, de-identification by reference number, and separation of personal details from genomic data).



A facilitator in conversation with a group of participants at the East London workshop.

What would build trust

Across all groups, participants were consistent in identifying trust-building requirements. The strongest thread was that trust must be built through honesty, not reassurance. Participants repeatedly said they wanted Genomics England to be upfront about limits: limits to data security guarantees, limits to what risk scores can predict, limits to the diversity of the current research library. They explicitly preferred honest acknowledgement of uncertainty and identified that overpromising and underdelivering would destroy community trust.



Participants taking part in a group activity during the East London workshop.

Specific trust-building measures identified across the groups included:

- Clear and accessible explanations of data governance;
- Opportunities for ongoing consent and the ability to withdraw consent at any point;
- Independent oversight and accountability mechanisms that are genuinely independent of government;
- Transparency about who can access genomic data and for what purposes;
- Regular communication and updates concerning how their data is being used;
- Options to choose different levels of participation and data sharing;
- Community representation in advisory or governance structures;
- Feedback mechanisms demonstrating how community input has influenced decisions;
- Mechanisms to keep participants informed about any changes or any data breaches;
- Evidence of how data from under-represented communities had led to health improvements for that community.

4.3 Histories and Harms

Experiences of discrimination in healthcare and other institutions

Participants across all communities described being discriminated against, or having their views dismissed or not listened to by doctors because of their gender, ethnicity, language skills, and social status.

I remember when my father passed away, and I've never... I don't even take paracetamol... But I was prescribed, like a liquid antidepressant. And I was like, "But I wouldn't take this." And I remember the doctor saying, "Oh, just take it." But I wasn't offered any sort of alternative. And then I went back a few weeks later, still feeling absolutely awful. Obviously, I was grieving.

Participant, Bradford

I mean, I find in a lot of Caribbean communities in particular, we have that mindset of, you know, Babylon system. And they're just trying to know what we're about. They're watching us. So, that's going to be a lot of the mindset behind, why do they want to know this about us? What are they trying to control? Are they then going to create something that they're saying is for us, but to kill us?

Participant, Birmingham

Discrimination was described by participants as being seen as a lesser person or inferior in some way and made to believe they mattered less.

Such experiences were compounded by systemic failures including long waiting times, limited budgets, overstretched services, and 10-minute appointments that did not accommodate complex health conversations. The GP consultation process was described as guesswork at times.

The pandemic was referenced as an example of this where vaccination refusal was connected to broader distrust of government motives. One participant described sons who refused Covid-19 vaccinations due to conspiracy theories about government intentions.

Experiences of discrimination were felt beyond healthcare, and across participants' social and professional life. Participants were consequently concerned that genomic technologies could amplify these biases – for example, that a predisposition to illness could be used to discriminate in employment ("what's to say our very specific information won't be used to sideline us from jobs?") or create "collective harm" for communities if data is misinterpreted or used to stigmatise.

Participants raised concerns about the stigma already associated with higher frequencies of disabled children born to Asian families in Bradford arising from "marrying cousins".

For some participants, these experiences raised concern about the use of genomic technologies for eugenics, wherein genomic differences become labelled as "abnormalities" and "defects" that need to be corrected, rather than seeing the person as someone's child.

I don't want to know if, you know, my child was gonna be born with a disability because that won't have changed my opinion. Of having the baby or not...

Participant, Bradford

For African communities, genomic testing was also associated with a need to prove biological relationships (especially paternity) for immigration purposes. This in turn could be stigmatising and, in some cases, had led to families being "torn apart" by paternity disputes. While the term gene rather than DNA had fewer negative associations, it was also less clearly understood than DNA.

Additionally, a significant finding from African participants was the fear that genomic information could stigmatize individuals or negatively affect their children's marriage prospects if a genomic risk is known within the community. Participants highlighted the moral dilemma of whether to share their risk with partners or family members, noting that this information affects the whole community, not just the individual.

It can stigmatize the individual to know... It could affect marriage chances for your children if there are risks of disease... The burden of this info doesn't just affect the individual.

Participant, Birmingham

4.4 Information and needs

4.4.1 General information and access needed concerning genomics research studies

Understanding of genomics and health

Broadly, participants had a good intuitive grasp of genomics and DNA (seeing it as the code for life). This notwithstanding, particular words: genomics, genome, genetics, genes, DNA, sample, felt too complicated or clinical, with few comparable words in mother tongue.

Participants felt that rather than providing written definitions of technical terms, Genomics England should convey the meaning and purpose of the study using metaphors and analogies. Participants had strong and positive associations of genes related to family, rootedness, and ancestry. In this context, metaphors, such as the 'tree of life', were particularly potent as it explicitly enabled people to visualise their past, present and future, and in this context articulate hopes and concerns around the use of genomics. Participants in East London even suggested that the Tree of Life should be the logo for the study.

Likewise, when learning about the study, several participants said they preferred verbal explanation over written information, and wanted real, specific examples to make the topic feel "a bit more real", for example, how genomics can influence someone's health.

Participants also had a good and intuitive understanding of how the combination of genomic and lifestyle factors could influence their health. As well as genes, they identified a wide range of risk factors contributing to their health, including diet, exercise, pollution, mental health, stress, financial situation, family dynamics (including controlling partners restricting access to healthcare), sex, age, weight, and occupation.

Participants also recognised grey areas, for example, a person's weight was not just related to their diet and exercise, but can be influenced by medication, their mental health and different life stages (such as the menopause or older age). Participants also stated that, for genomic research to be useful, it needs to take a holistic approach and should not ignore environmental or systemic issues.

Groups in Birmingham and East London expressed concern that their communities faced increased long-term health conditions, such as asthma and diabetes, that they had not heard of in their ancestral home. This was attributed to ultra processed foods, air pollution, economic pressures and the stress of working in the UK. One group mentioned epigenetics, believing these factors change health outcomes for children and suggesting that genomic risk is heavily influenced by the environment.

Participants found simple ways of visualising and illustrating risk to be effective – for example, particularly helpful was the use of Lego bricks to show how genomic risks (blue bricks) combine with lifestyle factors (green bricks) to provide a cumulative risk score.

Despite this understanding, participants generally viewed genomic information as predicting health risks more reliably than social or environmental factors. This deterministic view of genomic information also influenced whether participants believed the risk was personally actionable – essentially, lifestyle choices were viewed as less effective if a person had a genomic predisposition to a condition.

In the same vein, participants wanted to understand how risk would be communicated and the extent to which it was within their control. Consequently, they asked for health and wellness advice, such as changes to lifestyle, to be shared alongside risk information.

I want to be healthy and well—not living with lots of illnesses. Doctors should be giving us more information to stay well.

Participant, East London

I want to know all the info that is relevant to my risk.

Participant, Birmingham

Whole foods vs processed foods—is there a correlation with illnesses and what could they develop into a disease?

Participant, Birmingham

Raising awareness of the study

To raise awareness of the study overall, participants recommended a layered information approach: short initial information (poster, flyer, brief announcement) with signposts to more information for those who want it. Digital exclusion among older generations means online-only approaches will miss a significant segment of the target population. Rather, sustained, multi-channel exposure was seen as essential as a one-off announcement would not work. People needed to encounter the message through multiple touchpoints to raise awareness and generate community discussion, with community TV channels highlighted as particularly effective.

Despite this, participants also stressed that digital was both a powerful and ubiquitous means of communication. WhatsApp groups are one of the main sources and ways to share information among community groups for whom English is not a first language. Participants also mentioned Tik Tok as an effective platform.

After raising awareness and generating interest, participants then wanted practical information about the study: what's involved, how long it takes, how it links to other parts of their NHS care, and how their genomic information will be stored. Participants identified four primary routes to gain more detailed information:

- GP surgeries were seen as the most trusted setting;
- Places of worship were also recommended as trusted routes for sharing information. For Muslim communities, this included mosques, where a brief announcement at Friday prayers, before the imam's sermon, was seen to reach a 'captive audience', subject to prior permission from the mosque management committee;
- Community centres and community events were suggested because existing health outreach already takes place there;
- Schools were recommended because parents take school-originated information more seriously, especially where children's health is implicated.

On messengers, GP endorsement was seen as important, supplemented by trained community professionals with established local relationships. The idea of community champions was also valued; local people who have been through the study and could explain it in the community's own language, grounded in personal experience. For example, one participant served as a Covid-19 champion and made NHS videos in mother tongue. NHS-branded YouTube videos in mother tongue were also suggested as a trusted information source.

Several groups emphasised the need for community ambassadors or peer researchers, investment in relationship-building prior to recruitment, and working closely with trusted community and faith-based organisations.

Community leaders would have to be involved – they can help community members understand the importance of taking part and help with language barriers.

Participant, East London

Several participants said they wanted to hear not just from Genomics England but from pharmaceutical companies that use genomic data, researchers who would access the data, and the healthcare professionals who would deliver results. The main reason participants wanted to hear from these groups is to understand their hope and concerns about the study, their motivations for wanting to access genomic data, and how their data will be used. As well as raising awareness of the different groups that would be involved in the study, it would also build trust.

4.4.2 Information and access needs in the detailed study design

Taking part in the study – sample collection

Most participants preferred sample collection at a GP practice rather than at home. Attending a clinical setting lends credibility and seriousness to the process, makes people feel more obligated to follow through, and means someone is present to answer questions. Participants contrasted this with the negative experience of Covid-19 home-testing kits (such as uncertainty about whether the swab was done correctly and confusing instructions). One participant noted that for something new and unfamiliar, doing it in a trusted clinical environment with a professional reduces anxiety. Another pointed out that if something arrives by post, it is likely to sit on the sideboard and never get done. However, a home saliva kit with clear pictorial instructions was accepted as an alternative for accessibility purposes.

Nigerian participants were more evenly split on the opportunity for home testing, which was valued for convenience and privacy. That said, GP-based testing was viewed as more reassuring and medically supported. They suggested that Genomics England should manage testing stations within GP practices to help reduce overload on the NHS. Furthermore, due to the fear of discrimination and social stigma, some African participants in Birmingham would want testing to stay within the professional setting to hinder testing being done “under duress”, for example, people being forced to provide a test as a condition for marriage approval.



Participants taking part in a group activity during the East London workshop.

Delivering risk score findings

Participants across groups differentiated clearly between how negative and positive findings should be communicated.

Negative/benign findings: A letter or text message was considered acceptable to feedback on negative or benign findings. However, participants insisted they must receive some feedback as silence after testing would create anxiety and suspicion. The communication should include a note that further findings may come from the same sample in future. For people who cannot read English, a phone call in a community language was preferred, or alternatively a letter that could be shown to a family member for translation.

Elevated risk findings: Participants viewed getting feedback on elevated risk of a

condition as a personal and family decision that would differ in terms of how people were feeling, the nature of the risk, and what they could do about it. The consensus was that the choice to get feedback should be well-informed and genuinely voluntary, with clear examples of what kinds of findings might come back (treatable vs. untreatable, common vs. rare, immediate vs. future-onset). As noted earlier, while most participants said they would like to get feedback about an elevated risk of a condition, they expressed concern that providing genomic risk information could exacerbate mental health issues and anxiety, particularly given the NHS's inability to provide adequate follow-up support. Groups mentioned the need to always consider psychological support after test findings are shared with a participant.



A discussion amongst women at the East London workshop.

If feedback was given, participants rejected receiving detailed diagnostic information by letter, describing this as “throwing a brick at somebody.” Instead, they wanted a short communication (e.g. via letter or the NHS app) inviting them to come and discuss results, followed by a conversation with a knowledgeable clinician. A phone or video call was preferred for initial follow-up (as it was faster than waiting for a face-to-face appointment), with face-to-face also available for more complex cases. The maximum acceptable wait for specialist follow-up was stated as 3 to 6 months; beyond this, anxiety and trust erosion sets in. This was treated as a red line.

One group suggested a red-amber-green (RAG) system to determine who needs which resource, based on risk, severity of condition and need:

- Red: one-to-one therapy;
- Amber: group discussion;
- Green: information on managing anxiety.

While participants ideally wanted GP involvement at key stages (sample collection, results discussion), they accepted that alternative models like trained study clinicians, genetic counsellors, phone/video triage would be necessary to make the study viable. They emphasised the need for empathy and a “human touch” in delivery, noting that some GPs are not great at eye contact and use complicated language.

Participants also wanted the option of a specialist-led session with the whole family, to ensure everyone heard the same information. The rationale was that relying on one person to relay genomic information leads to dilution, misunderstanding, and inconsistency. Specialists leading these sessions would need training in communicating with children about serious health topics in age-appropriate language.

We need a support plan for the family as well. Mental health is a family and a community issue. Any one bit of misinformation will have a serious impact on efficacy.

Participant, East London

Feedback about the effectiveness of medicines

Pharmacogenomic information was generally seen as less complex information than that related to an elevated risk of a condition. Consequently, providing it was simple and clear, pharmacogenomic information could be passed back to both the healthcare professional and the participant without the need for broader support. This could include digital options for feedback to participants such as the NHS App or secure email for

straightforward results. A key requirement was for the information to be available at point of need (for example, prescribing decisions).

Participants were invited to discuss a hypothetical case study concerning getting feedback on the effectiveness of statins. In discussing this, participants said they wanted to have information on the risks of both taking and not taking statins, and other available medications. They were also keen to ensure that patients were provided with information about lifestyle changes that could make a difference to their health, not just the medication – for example, changes to diet to lower cholesterol.

Related, several participants expressed a strong preference for non-pharmaceutical approaches to health, including herbal medicines, social prescribing, talking therapies, and holistic approaches. There was frustration with what they perceived as the over-prescribing of medicines by GPs, particularly for conditions like headaches, stomach aches, and depression.

Language and dialect

Participants were mindful of words getting lost in translation when feeding back health information. For example, participants recommended using the Sylheti dialect rather than standard Bengali for Bradford's Bangladeshi community. Standard Bengali was described as the language of "government and learning" and is less accessible to older generations. The majority of Bradford's Bangladeshi community speaks Sylheti.

Additionally, a wide range of health conditions did not have a clear translation in various community languages, which in turn could lead to misunderstandings or reinforce stigmatisation. For example, there is no word for mental illness in Sylheti – rather the term 'fagol' (meaning crazy) is often used pejoratively. For the Pakistani community, the absence of Urdu equivalents for the words such as 'menopause' and conditions

such as Alzheimer's were also flagged as risks concerning how serious issues may get lost in translation. Somali does not have a translation for depression.

Participants across the groups mentioned the need to communicate in plain English using language that is easy to translate and culturally sensitive. People can only understand if they are given information in a way that is useful and accessible.

Countering misinformation

Participants were acutely aware that self-directed online searching can produce unreliable and alarming information. One participant described Google as causing "more doubt" because different websites give contradictory information. The group strongly recommended that at the point of receiving results, people should be directed to specific, curated, NHS-vetted resources, ideally a dedicated NHS web page and/or video in mother tongue.



A discussion amongst women at the East London workshop.

4.5 Consent, lifecourse and responsibility

Family as the unit of engagement

Across community groups, participants consistently reframed the study from an individual health intervention to a family one. Whether discussing data security fears ("what happens to my children if my data is misused"), risk of a condition ("I want to know so I can prepare my children"), recruitment

(“I will take part for my children’s health”), or result delivery (“I want a family session with a clinician”) – the family was the operating unit.

Family dynamics and coercion

Participants also mentioned that household dynamics may also prevent family members from participating in the study. Specific scenarios raised included: a husband who does not want his wife to take a test because he does not understand it or would prefer not to know; or domestic violence situations where a controlling partner might physically prevent someone from attending a blood test.

As genomic findings have implications for family members (children and siblings), this created tensions that needed to be thought through. The group felt Genomics England could not solve such tensions directly but should factor them into study design by considering family-level engagement from the start and framing the study around protecting children’s futures as well as individual health.

Consent across the lifecourse

A recurring concern was whether consent to use genomic data for certain purposes given at one point would hold meaning over time. The Pakistani community described a “slippery slope” scenario in which genomic data collection becomes normalised and eventually expected or even mandated. Participants could see genomic data collection “soon becoming something that is expected of people to provide” including the potential for government-mandated genomic testing. As mentioned earlier, there were several concerns regarding how government may use genomic data, such as targeting and harming minority communities (with the plight of Palestinian people cited as an example), and use the genomic information to track and control people.

Several groups raised the question of what happens to genomic data after death. One participant asked:

In 40, 50 years’ time, I’m dead. Will they hold on to my information? Would I want that information to continue being in someone’s database when actually I then can’t give consent?

Participant, Bradford

Another wanted periodic consent review: if Genomics England intended to use data for a purpose the participant might not agree with, she wanted to know and to be able to judge whether she considered it ethical.

Religious dimensions

Participants acknowledged that some community members may see genomic testing as interfering with God’s will but felt this was increasingly a minority view. The recommendation was proactive engagement with imams and religious leaders through dedicated briefings, so they could address theological concerns from a position of knowledge before they became barriers to uptake.

Responsibility and doing right by communities

A cross-cutting finding was that the research was asking a lot of communities who are “facing huge inequalities and have been let down by power structures in the past.” They questioned what guarantee there was that researchers and companies would do right by their communities, and that medicines and treatments work properly for their community.

There were several aspects of how the study could do things better in the future. These include:

- **Health literacy:** participants saw significant benefits in engaging people and communities in conversations about their health and enabling people to access, understand, and use genomic information to make informed decisions about their health and care
- **Feedback:** health information feedback was an essential part of a 'fair deal' for taking part in the study. All feedback (even null results) means someone's contribution is acknowledged and matters. Participants gave examples of other health research programmes or medical tests where feedback either did not happen or was done in a perfunctory way. Such approaches were considered extractive and undermined trust.
- **Empowerment:** information also empowers communities and people to have better conversations about their health, either by shaping relationships between healthcare professionals and patients, or by raising awareness of health issues at a community wide level.

It changes across generations. For my parents [mental health] is completely taboo. It's less so for my generation... but in general it is just not talked about. Having this information and getting the community involved can help start a conversation.

Participant, Birmingham

Participant, Bradford

- **Honesty about system limitations and constraints:** participants were very aware of the pressures facing GPs and the wider healthcare system. They are also aware that any new technology can bring benefits as well as harm, and it was not possible to guarantee that genomic information could not be misused. As well as working to minimise the impact of these issues, the study needs to acknowledge the concerns and discuss them openly for trust to be built.



Participants taking part in a workshop discussion in Birmingham.



A flipchart diagram showing the Genomics, Healthcare and You engagement strands.

5. Conclusions

In this section, conclusions are drawn across the community engagement workshops that have implications for the design of the planned study into the use of genomics in adult population health and the wider governance of genomics in healthcare and research. They relate to trust, agency, systems design, and how communities evaluate risk and benefit.

Community embedded genomics requires co-design and long-term relationships to build trust

Across all areas, participants were not simply weighing ‘genomics’ as a technology; they were evaluating the institutions and systems that would hold and act on genomic data. Trust was repeatedly described as conditional: built through transparency, reciprocity, and credible oversight, and eroded by histories of discrimination, perceived inequity, and poor service experiences. Significant time was spent working with communities in advance of the immersion phase to build the needed trust to begin a conversation on genomics. The motives of Genomic England were an important part of building trust and confidence for communities to participate. A place-based approach to engagement is likely to be needed to build the relationships and social capital for success.

Hope and benefits are real, but they must be locally believable

Participants valued prevention, early diagnosis and better treatment, often framing benefits through family wellbeing and future generations. However, hopes were mediated by whether genomics felt connected to people’s lived experience of the NHS (for example, difficulty accessing GPs, long waits, fragmented care). Participants were concerned that the use of genomics in healthcare could exacerbate problems, especially in relation to feedback on elevated risk. Trust will be contingent on getting

feedback and support right. Participants were worried about the impact on an already overstretched NHS providing this.

Consent should not be a one-off event but an ongoing relationship

Across areas, consent was discussed as a continuing right: to understand, to choose, to change one’s mind, and to control secondary uses. Concerns intensified where people anticipated “scope creep” (third-party access, commercial profit, or future governance shifts).

While a detailed consent process was not discussed, generally, participants wanted periodic opportunities to update their consent for both how their data was used in the NGRL and feedback they may receive by engaging in the study. This should include the right to withdraw from the study. Ideally, ongoing consent would be actively driven by Genomics England, rather than relying on participants to remember to update their preference. Certain participants wanted to be asked for consent during every use case, including any access to their data in the NGRL, though they had not considered the costs and administrative challenges involved in this process.

Consent would also be contingent on other communication and feedback, including regular communication and updates on how their data is being used and the health benefits this has brought to individuals and communities.

Data harm is anticipated through the lens of structural racism and surveillance

Concerns about privacy and misuse were not abstract. Participants drew on real experiences of discrimination and institutional power. This included fears of profiling, stigma, and non-health access to data. In some narratives, the possibility of genomic data being weaponised was linked to broader anxieties about racialised control. Linked to the point on consent, providing opportunities for participants to withdraw from the study should they have concerns around access to, or wider use of, their genomic data is an important safeguard.

Information, language and meaning-making are not 'nice to have', they are safety mechanisms

Participants want the study to be communicated in plain language, using visual explanations, and culturally relevant terms. Lack of accessible information was linked to misinformation, misunderstanding, and reduced willingness to participate. Some emphasised that knowledge can be a route to trust and participation, but only if delivered with care and time for dialogue.

Intergenerational ethics and 'future-proofing' are central to legitimacy

Participants raised questions about what happens to data after death, how future governance could change, and how communities can be protected over time. This intergenerational lens was particularly strong where 'good ancestor' framing resonated.

Participants at the Birmingham workshop.



6. Recommendations

In this final section, recommendations are identified for future community engagement, the study design, Genomics England and healthcare professionals.

Recommendations for engagement practice

- A place-based approach to community engagement is vital but may be challenging for Genomics England to achieve in practice, given resource constraints. There are several large UK health research programmes and longitudinal population studies which face similar challenges concerning the diversity of study participants. Genomics England could convene a session to explore whether a strategic approach to engagement and shared learning could be adopted amongst similar organisations.
- Related, there is a need to resource community-led outreach via people trusted within the community. This is likely to mean investing time and resources over a longer term to build capability and advocacy within communities. It also means proactive engagement with imams and religious leaders through dedicated briefings, to address theological concerns from a position of knowledge before they became barriers to uptake. To realise the value of this investment, a long-term view should be taken of how communities can be involved ongoing in programmes across Genomics England and beyond.
- Clear communication is the bedrock for effective engagement practice. It will be important to embed mother-tongue facilitation and interpretation as standard where needed; retain back-translation services to ensure the meanings do not get lost in translation; and embed participant sense-checking to strengthen how findings are interpreted.
- The engagement approach should build knowledge with communities using plain language, visual tools, and culturally relevant framing: using plain language, visual explanations, culturally relevant terminology, and allowing time for questions. The study should treat building health literacy as part of the engagement offer.
- Genomics England's reliability and credibility are central to building trust, and enabled by embedding feedback mechanisms in the design. This could include 'communication loops' showing how genomic information is used, reporting back the benefits to communities of their involvement, and avoiding perceptions that data is misused.
- Within the three areas engaged within this research, a tailored approach to community engagement has been central to success. A key learning from the engagement has been to keep methods flexible and locally responsive, while maintaining a consistent ethical spine (consent, agency, safety, transparency). To assist this process, a summary of the strengths and limitations of the techniques employed through the engagement process is shared in the Technical Appendix.

Wider governance recommendations concerning the study, Genomics England and the broader healthcare system

The research study

- **Consent:** while many participants wanted an ongoing active consent model, how this would work in practice was not discussed. There would be significant challenges and costs associated with an ongoing consent process operating across the NGRL, given the large number of studies and participants involved. Given the importance of this issue to communities, a workable solution needs to be found. It may be the case that regular communication about the study at a general level, together with information about withdrawing from the study (as desired), is sufficient. It is recommended that Genomics England co-develop potential consent models with communities.
- **Data management and access:** there is a need to develop clear information concerning who can access participant data, for what purposes, and what independent oversight exists. While a 'reading library' analogy was helpful to illustrate how data could not leave the NGRL, participants were unclear about the relationship between de-identified data in the NGRL and return of findings for clinical practice. A simple, pictorial way of showing data flows, governance and safeguards should be developed.
- **Data diversity:** active steps are required to ensure genomic data held in the NGRL is diverse. Equity should be treated as a design requirement and placed at the forefront of communications about the study. With this in place, the lack of diversity in existing genomic datasets can be used to motivate communities to participate in the study. Transparency about uncertainty, the limitations of the data and how bias is addressed is an essential part of a fair deal for participating communities.

- **Returning findings:** One of the greatest challenges to the success of the research study concerns the return of findings, given the pressure on an overstretched primary care system. Participants wanted the opportunity to speak with specialists who could provide clear, step-by-step explanations of the risks and how they could be managed. It is not clear that the healthcare system has the capability or capacity to deliver this at a population level, or that these needs are accounted for in workforce planning. Providing clear proof points on how such an ambitious programme will be delivered, given lived experience of current healthcare, will be important to build trust.

Genomics England

- **Future access to data:** participants wanted a guarantee that researchers and companies would do right by their communities. Given the changing political climate, participants were particularly fearful of access to their genomic data for non-health purposes (for example, for policing or immigration) Participants want Genomics England to explore the potential for a constitution setting out safeguards concerning the use of data by the state and the private sector, and associated options for participants to withdraw from the study.

Healthcare system

- **Findings efficacy:** Central to a fair deal for communities participating in the study was that medicines and treatments work properly for them. This will be hard to achieve in practice given limitations to the predictive power of genomic data (for example, uncertainties around polygenic risks scores in clinical application) compounded by a lack of diversity in current genomic datasets. Thought needs to be given to how benefits are not oversold to communities given this context, and also how these uncertainties are communicated when findings are returned.

Acknowledgements

The Social Agency, People Street and The Leap would like to thank all the participants in the inclusive communities strand of Genomics, Healthcare and You who explored the topic with such care and thoughtfulness. Their commitment to their responsibility to discuss their hopes and concerns around the research study and any future roll-out of genomics in healthcare was impressive and profound.

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 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 all participants shared a range of perspectives and covered the key issues under review.

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.

[Participants at the Birmingham workshop.](#)



September 2026

Genomics, Healthcare and You

Inclusive Community Engagement Report

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The Social Agency and The Leap

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