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Genomics, Healthcare and You

Public Dialogue Findings Report
Prepared by HVM



**Hopkins
Van Mil**



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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 research 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, 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

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.

Grounded theory: A qualitative research tool which develops theories directly from systematically collected and analysed data. The approach emphasises iterative cycles of data collection and analysis, allowing emerging concepts to guide further inquiry. Grounded theory was selected to analyse the public dialogue as it works well in explaining processes, actions, or interactions over time, particularly in under-researched or complex contexts.

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.

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

Executive summary

Public dialogue purpose, format and scope

Genomics, Healthcare and You is an engagement programme commissioned by Genomics England in October 2025 and delivered by a partnership of organisations led by Hopkins Van Mil (HVM).

This report covers the public dialogue strand, which HVM led.

Genomics, Healthcare and You will inform the design of the Adult Population Genomics Research Study (the research study) and its longer-term ambition to bring genomic research and medicine into wider healthcare. The research study aims to sequence the genomes of around 150,000 adults and explore how genomics could be used in routine, preventive care.

The overarching questions for the engagement programme were:

- 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?
- 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?

Two uses were explored:

- Pharmacogenomics (PGx), which uses genomic information to tailor medicines and avoid adverse reactions
- The return of findings on actionable risk of some common conditions.

The public dialogue involved 112 participants, broadly reflective of the population of England. Participants met in person over two weekend workshops in London and the South East and in Newcastle and the North East. The workshops were supported by an online briefing and a dedicated online space.

Genomics for preventive healthcare: conditional optimism

The overarching message from the dialogue is one of conditional optimism. For many participants, genomics is both amazing and scary. They can see real potential to prevent ill health, tailor medicines, reduce side effects and strengthen research, while at the same time holding deep concerns about how genomic data might be used beyond health and the risk of widening health inequalities.

A notable shift for many participants is that over the course of the dialogue they came to see genomics not as a higher truth or a verdict, but as one more piece of health information to weigh alongside others. In participants' own framing, genetics moved from being treated as 'Gospel' towards being seen as part of a jigsaw. There are also concerns about decisions made carefully now being undone by a future government; or the use of genomics reaching out of healthcare into other aspects of public life such as immigration policy – which participants saw as unacceptable.

Genomics as part of a wider framework for better health

Participants are clear that genomics does not operate in isolation. They place it within their experience of an NHS they see as underfunded and overstretched, and within a wider political climate they find uncertain. Many drew on present-day concerns about how health and other data can be used, and on enduring questions about fairness, to explain their caution. A strong and recurring hope for the NHS is that genomics forms part of a genuine shift from a treatment service to a prevention service, sitting alongside support on lifestyle, nutrition and wellbeing.

Pharmacogenomics: tangible benefits

Pharmacogenomics is broadly understood and widely supported by participants. Its benefits feel clear, objective and tangible. They recognise the suffering caused by a trial-and-error approach to medicines, the burden of side effects, and the waste caused by medicines that are ineffective. Many can see how getting the right medication and dose sooner could build trust, improve the likelihood that people keep taking their medicines, and save the NHS and patients time and money. Some value the prospect of personal access to their own PGx information as a way to advocate for their care, particularly in cases where they have felt dismissed in the past.

Pharmacogenomic concerns centre less on the research study and more on a wider roll out. Participants worry that PGx could reinforce a drug-first culture at the expense of lifestyle and more holistic approaches. There is particular unease about its place in mental health, which they see as complex and multifactorial. Some fear that:

- Findings could be treated as deterministic and reduce patient agency;
- Healthcare professionals (HCPs) across the country might not be trained to use the information well;

- Profit motives among pharmaceutical companies could shape how it is used to the detriment of patients.

There is broad agreement that PGx information should be available to HCPs across the NHS to inform urgent and ongoing care. They believe patients should have a say in prescribing decisions, and that PGx for medicines should be treated as one tool among many rather than the only answer.

Actionable risk: qualified support – more evidence needed

The return of findings on actionable risk is welcomed as a concept, but views are more conditional and more cautious than for PGx. Because genetics is seen as fixed and certain, a high-risk finding can feel like a diagnosis-in-waiting. Many participants hope that knowing about risk early could help people act, plan for the future and access more tailored screening, on the principle that prevention is better than cure.

Participant concerns are significant. They worry about the:

- Anxiety that risk information can cause
- Findings being more reliable for some groups than others given the lack of diversity in existing genomic data
- Additional burden on an already stretched NHS from people seeking support for their findings
- Benefits flowing mainly to wealthier and better educated people unless the healthcare actions that stem from the risk information are genuinely accessible to all.

Responses varied by condition. Three conditions were specifically discussed through case studies: cardiovascular disease (CVD), cancer and dementia. CVD is seen as the most straightforward and acceptable condition to receive a risk score for, because clear actions and preventive treatments exist. Cancer discussions often focused on

the potential to tailor screening based on risk scores. Dementia is most concerning for participants given the absence of a cure, or proven ways to slow its progress, and the evidence about risk identification is weaker. Many feel that polygenic risk scores (PRS) need further research before they are used to guide health actions.

Small group discussions at a London workshop.



Participants point to middle age, and to the existing NHS Health Check from age forty, as a sensible time to share risk. They expect to receive findings through the NHS App, with the option to speak to a person such as a nurse, condition specialist or pharmacist, particularly if they have an elevated risk score. Additionally, participants expect that risk information will always come with clear, personalised actions, and with lifestyle changes offered before medication when appropriate.

Genomic data only used for public good in healthcare

Many participants support de-identified genomic data being used for medical research, seeing benefits for themselves, for society, and for future generations. At the same time, the unique and personal nature of genomic data, raises concerns that go beyond ordinary health data. Participants want to understand where data would be stored, how it would be protected, and who would have access. They are worried about de-identified data being re-identified and about genomic data, given by individuals

to benefit their own and others' health data, being used to generate private profit in ways that are detrimental to public good.

The strongest and most consistent message across the whole dialogue is that genomic data should only ever be used for health, never for purposes such as immigration, policing, insurance or employment. This goes with the belief that safeguards are needed to prevent mission creep should priorities or governments change.

Barriers, enablers and research study design

Participants identified barriers that could hinder the research study and any roll out if the evidence supports it. These include the cost, and how funding is prioritised when the NHS is already under strain; a health system they see as disjointed; the lack of diversity in genomic data, and uncertainty about whether the outcomes would justify the investment.

The enablers they point to mirror these concerns. They include: strong governance and regulation, particularly on access to and use of genomic data; sustained public awareness and education; transparency about what is and is not involved; action to improve data diversity; a proper support system for when findings are shared; training for HCPs; well-integrated IT systems such as the NHS App, and careful international collaboration, where trust can be assured, to diversify data and speed up research findings.

On the design of the research study itself, participants want consent to balance simplicity with genuine choice. This includes the option to take part in research only, to receive personal feedback only, or both. Many expect consent to be handled digitally through the NHS App, with a human option to discuss consent for those who want it.

Hopes and concerns for genomic healthcare

The table below summarises the contrasting hopes and concerns associated with

genomics and health, which are explored in greater depth throughout this report.

Hopes and concerns for genomic healthcare.

Hopes	Concerns
NHS	
Prevent illnesses and side effects – reduce costs of treatment and reduce medicine wastage.	Overburden an already stretched NHS with cost of tests and follow up and supporting people made anxious by their risk scores – taking money away from vital basics.
Data	
Used in research to identify and treat health conditions.	Sold to employers and insurers; commercialised primarily for private profit over public good.
Innovation	
Prevention of health conditions; earlier diagnosis; new and better treatments.	Cloning; designer babies; eugenics.
Treatments	
Personalised medicines and therapies, more focus on holistic health (non-drug), and reducing side effects and medicine waste.	More focus on drug interventions – less on lifestyle and environment.
Genomics	
Guides towards better health alongside other factors e.g. lifestyle and environmental factors	Risk is in effect the same as diagnosis and the potential to be affected by a condition identified in a risk score feels inevitable.
Personalised understanding of my health.	Whole genome data may feel deeply personal and invasive.

Recommendations

Participants drew their deliberations together into a set of recommendations that reflect their conditional optimism. In summary, they ask that the programme:

- Keeps data secure and used only for public and personal health, protected by a legal framework or constitution against decisions by any future government to allow use of genomic data which crosses participants' redlines;
- Rights the wrongs of past genetic research by making diverse and representative data a priority, working with communities at a grass roots level to build trust, including through over-representation in the data and in research studies where this is needed for equity;
- Treats informed consent as crucial to trust, keeping it clear and concise while offering real choice over how data is used and what is returned;
- Builds public understanding through transparent communication that shares failures as well as successes, and that reaches all communities;
- Supports people receiving findings so that risk is demystified, meaningful, paired with actions, and offered with the option of personal contact for higher-risk results;
- Focuses first on pharmacogenomics, and on CVD as the most acceptable condition for risk feedback, while strengthening the evidence base for risk scores;
- Recognises genomics as one tool among many, working together with lifestyle and environmental factors that shape health;
- Demonstrates its return on investment to a public that sees the NHS as precarious and over-stretched;

- Puts in place governance and leadership informed by a wide range of perspectives, including members of the public, with long-term resilience and, if needed, a close-down plan for the programme that has data security as its highest priority;
- Supports HCPs through training;
- Stores genomic data securely and preferably in the UK;
- Pursues international collaboration to enrich data diversity and speed up discoveries.

Taken together, the dialogue suggests real public goodwill towards the use of genomics in preventive healthcare, provided the foundations are laid carefully now. Participants are hopeful about what genomics could offer. They are clear that this hope rests on data being protected and used only for health and health research; on benefits reaching everyone rather than a few; and on the NHS being supported to deliver it well.



Small group discussion at a Newcastle workshop.

1 Introduction

This chapter is an introduction to the report on the public dialogue strand of the Genomics, Healthcare and You engagement programme. It describes the context in which the programme was developed. It explains Genomics England's role as the commissioner of this significant programme of engagement and introduces the work done by the partners in the engagement programme.

1.1 Background to the engagement

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

In partnership with the NHS, Genomics England launched the Generation Study in 2024, a research study that will sequence the genomes of 100,000 newborn babies to evaluate whether whole genome sequencing could support earlier diagnosis of rare genetic conditions.

Genomics England has now been funded by government to run an Adult Population Genomics Research Study (the research study) which is being designed to evaluate the benefits and implementation of population-level genomic screening in

healthcare. This is set out in the NHS [10 Year Health Plan for England: fit for the future \(GOV.UK\)](#) and the [Life Sciences Sector Plan \(GOV.UK\)](#), which references a large-scale study to sequence the genomes of 150,000 adults and assess how genomics can be used in routine preventive care.

1.2 What the engagement set out to achieve

The [Genomics, Healthcare and You](#), engagement programme was commissioned in October 2025 and delivered by a partnership led by [Hopkins Van Mil \(HVM\)](#). The engagement with HCPs was led by [RAND Europe](#), the inclusive communities strand by [The Social Agency](#), [People Street](#) and [The Leap](#), and the public deliberative programme by HVM. The latter is the subject of this report. Each of the engagement strands is reported on separately by the lead partner. An overarching report sets out the findings and common themes from the full programme.

Genomics, Healthcare and You aimed to inform:

- the design of the research study;
- 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 all strands of the engagement process. The engagement programme was managed by a project team comprising Genomics England and the partner organisations. A sub-group of the Participant Panel at Genomics England provided guidance at each stage of the public dialogue process.

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 research study. 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 the public dialogue programme were:

- What are people's views about being offered and receiving genomic findings that could be used to personalise their medication?
- What are 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?
- 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?

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

Participants at the London public dialogue workshop.



2 Methodology

This public dialogue used robust deliberative methods and trusted design and delivery principles. It was conducted in three phases: scoping and design; fieldwork delivery; coding, analysis and reporting. This chapter explains how the dialogue was conducted, with the dialogue findings set out in the next chapter.

2.1 Principles guiding the public dialogue design

HVM is a social research agency specialising in public deliberation. For twenty-one years it has brought people together from diverse backgrounds across the population to inform public policy and decision making on the subjects that matter to us all – including health. HVM is guided by best practice in deliberation including [Sciencewise Guiding Principles](#). These principles include the involvement of an Oversight Group and members of the Participant Panel at Genomics England as previously described. Their role was to advise the delivery partner throughout the process and challenge methods to ensure they are fit for purpose and robust. In addition, public dialogue processes:

- Recruit a sample of people broadly reflective of the English population, with targeted recruitment of participants who have not previously had the opportunity to take part in discussions on policy that affects their lives
- Enable meaningful, safe and trusted interactions between participants with a range of experiences and backgrounds, supported by experienced facilitators
- Provide a range of inputs including specialist presentations and speaker panels, information sheets, case studies and scenarios, which provide evidence-based stimulus for participants' deliberations

- Allow sufficient time over the course of several weeks for participants to engage with these materials in workshops and asynchronously in a dedicated online space
- Create the conditions to deliberate on a clear task, policy or actions
- Use a grounded theory approach to reviewing the wide range of qualitative data resulting in a robust analysis, rooted in what participants have shared and discussed, not a hypothesis to be tested.

Our approach to each of these elements is set out below.

2.2 Who took part in the dialogue?

Carefully constructed criteria (Appendix B) were established to recruit approximately 120 people to take part in the public dialogue using purposive sampling. This method reduces the likelihood of bias in who is engaged in the dialogue. It ensures participants broadly reflect the demographics of the English population. The criteria were shared with the Oversight Group, Participant Panel members and agreed by the project team before recruitment began.

Targets were set for some demographics to make sure the dialogue was inclusive of a range of backgrounds and avoided over-representation of certain demographics, e.g., those with higher levels of educational

attainment. Targets were also set for the dialogue to involve people whose voices are rarely heard in engagement processes, recognising minoritised ethnic groups have been less well represented among research participants historically. The process also avoided marginalising minority perspectives in small group discussion and worked to ensure no one felt that their role was to represent a community or place.

Recruitment (and delivery) focused on two broad locations: London and the South East, Newcastle and the North East. The choice of these locations was based on ensuring a broadly reflective sample, as well as trying to locate the discussions in the proximity of research and clinical teams to support their involvement in the in-person sessions.

119 for 112 participants were recruited to the process working with our specialist fieldwork teams Acumen and Fieldmouse. Using on-street, panel and community networks the process engaged:

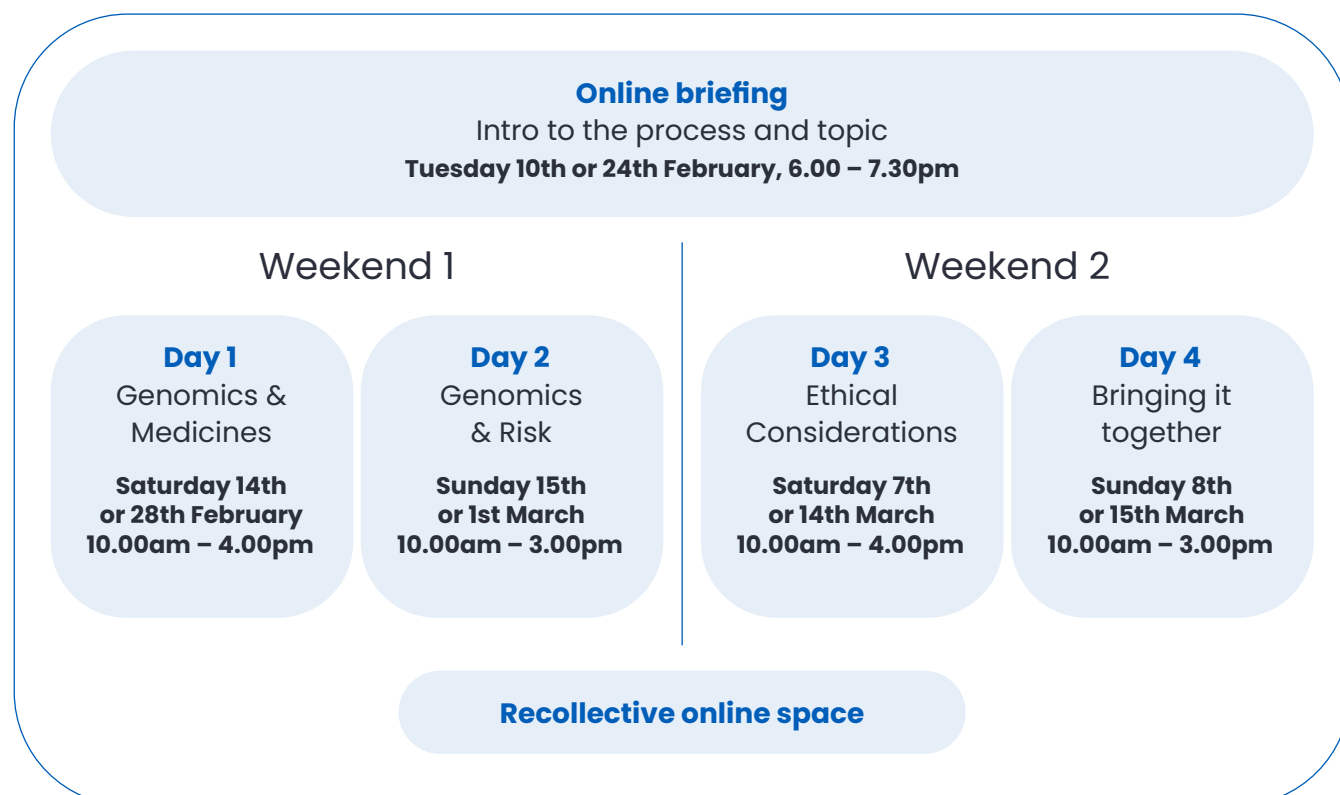
- **7 to achieve 6** public participants living in London to take part in a pilot process in January 2026
- **56 to achieve 52** public participants living in and around London & the South East in February and March 2026
- **56 to achieve 52** public participants living in and around Newcastle & the North East in February.

54 participants took part in all workshops in Newcastle and the North East, and 52 in London and the South East, a total of 112 participants including those who took part in the pilot.

2.3 What did participants do?

Participants took part in a public dialogue involving an online briefing, two weekend workshops, and participation in an online space (Figure 1).

Figure 1: public dialogue process elements



A pilot process took place in person in London over two consecutive Saturdays in January 2026. Pilot participants took part in a mini-process in which the deliberative plans were discussed and explored in two dialogue workshops. They tested draft scenarios for both pharmacogenomics and actionable risk. Changes made to the dialogue process as a result of the pilot included giving time at the start of the process to discussing views on and experiences of the NHS and introducing and supporting discussions on ethics.

In February 2026 the full public dialogue process began, taking into account the learnings from the pilot process. The process involved the following (Figure 1):

- **A tech support session** supporting those that needed it with guidance on taking part in the online session, including how to use Zoom and the loan of tablets, headphones, Wi-Fi hotspots and other equipment as necessary to ensure no one was prevented from taking part due to a lack of digital equipment or experience;
- **An online briefing** for participants with presentations from:
- Rich Scott, CEO, Genomics England who introduced Genomics England and its role, including the plans for the research study in the NHS 10 Year Health Plan;
- Ellen Graham, Service Owner, Adult Programme, Genomics England who introduced the research study and described what it was and was not intended to include.

Weekend 1 workshops: covering pharmacogenomics on day 1 and genomics and risk on day 2.

On day 1: participants heard from the following specialists speaking about the fundamentals of pharmacogenomics:

- **London:** Dr. John McDermott, clinician/academic, University of Manchester
- **Newcastle:** Hayley Wickens, Consultant Pharmacist, Genomic Medicine.

On day 2: the following specialists took part in a panel discussion on the efficacy, evidence and implications of the lifetime genome for the future research study.

- **London:** Sir John Burn, Professor of Clinical Genetics, Newcastle University; James Ware, Professor of Cardiovascular and Genomic Medicine, at Imperial College London; Dr Stephanie Archer, Assistant Professor of Psychology, University of Cambridge; Hannah Stark, Operations Lead, NIHR BioResource; Dr Ellen Thomas, Chief Medical Officer, Genomics England
- **Newcastle:** John Burn, James Ware and Hayley Wickens

Weekend 2 workshops: covering an exploration of the ethical implications of genomics in healthcare on day 1, and participant deliberations bringing thinking together to create recommendations on day 2.

On day 1: participants heard from the following panel members:

- **London:** Dr Natalie Banner, Chief Ethics and Engagement Officer, Genomics England; Dr Nayana Lahiri, UK NHS Consultant in Clinical Genetics; Aroon Hingorani, Professor of Genetic Epidemiology, UCL; Natalie Khoaz, Research Midwife, University of Sheffield; Dr Hettie Williams, GP; Felicity Boardman, Professor of Social Science in Medicine, University of Warwick.

- **Newcastle:** Paolo Buscemi, Ethics Lead, Adults Programme, Genomics England; Dr Judith Hayward, Principal Clinician, Primary Care, Genomics England; Bill Newman, Professor of Translational Genomic Medicine, University of Manchester; Sasha Henriques, Director of Equity Assurance, Genomics England; Felicity Boardman, Professor of Social Science in Medicine, University of Warwick, and Aroon Hingorani, Professor of Genetic Epidemiology, UCL.

During each weekend participants worked in small groups, and in plenary discussions, to explore the dimensions of Genomics, Healthcare and You in carefully facilitated deliberative sessions. Team members from Genomics England, NHS England and other stakeholders acted as observers for the workshops.

A summary of the programmes for each workshop is shared, alongside the scenarios and stimulus materials used, in the Technical Appendix which accompanies the four reports from Genomics, Healthcare and You.



Small group discussion at a London workshop.

2.4 Participant-led materials and questioning

An essential part of any dialogic process is for participants to bring their own views and experiences to their discussions, starting with where they are rather than where the science is. A dedicated online space was created for participants using a tailored version of the qualitative research platform Recollective to support this process. Here participants could re-watch presentations they had seen in the workshops, they also were able to watch pre-recorded videos from specialists. This included Dr Mavis Machirori, a senior researcher with the Ada Lovelace Institute who spoke about why the diversity of genomic data matters, and shared current figures on which ancestries are represented/ under-represented in health data.

Participants could use Recollective to think through the topic in their own time, ask further questions and raise topics for discussion. It is in this space, as well as in the workshop discussions, that participants were asked to share the findings from the interviews they conducted with one or two of their family members or friends between the two weekend workshops. They were asked to share with these interviewees what they had learnt in the process and ask them to consider how they feel about genomic data guiding which medicines are prescribed and being used to assess future risk of key health conditions such as cancer, heart disease and dementia. The views of family members were as diverse (hopeful and fearful) as dialogue participants and have been included in the findings analysis for this report.

2.5 Analysis and reporting

Public dialogue reports are qualitative in nature. As such they do not report on the number of times something was said, but rather the strength of feeling expressed across the methods used, with explanations of why participants felt as they did. This project used grounded theory, which means transcripts were read and re-read many times. What was said was collated into key themes and those themes were used to draw out meaning from the discussions. This approach was chosen to ensure the findings are rooted in what participants said, guided by the dialogue objectives and the research questions, rather than looking for confirmation of preconceived ideas.

The dialogue engaged participants who were broadly reflective of the population of England in demographic characteristics, who met in either London or Newcastle. Differences in views where these were particularly distinct for a specific location have been highlighted. Generally, commonalities, patterns and differences were analysed across the complete data set.

The following quantifiers are used in the report:

- 'Many' or 'most' when all or almost all participants shared a similar view;
- 'Some' when a reasonable number of participants shared a similar view;
- 'A few' when a small number of participants shared a similar view.

Bullet points are used to summarise key points made. These mostly reflect areas of agreement and where points were made by many participants across both groups. Public dialogue participants reflect together on the implications of a topic for society. For this reason, our analysis focuses on themes across the dialogue rather than differences in views by demographic group.

Anonymised quotations are used to highlight points made by participants and to underline points made by a range of people.

In writing this report, we use a combination of tenses. Generally past tense is used to describe what people said or did at a workshop. However, the present tense is used to describe participants' views, feelings and beliefs, because these are understood as current perspectives rather than views held only at the time of the dialogue.

Analysis of dialogue findings does not track how participants reacted to specific pieces of evidence, nor when they might have changed their mind on the topic or a specific aspect of it. Given the nature of the information, and the range of perspectives presented to them on it, they might have changed their minds a number of times during one workshop, and over the whole project. Significant shifts in attitude are reported on.

Throughout the process the HVM coding, analysis and writing team maintained a rigorous approach, holding sense-checking sessions as a team to mitigate against researcher bias. The purpose of the analysis is to meet the dialogue aims and objectives, accurately reflecting participants' views and sharing what they have found to be important in three dimensions: for the research study, for Genomics England's wider objectives, and for society as a whole as it considers the impacts of embedding genomics more widely in healthcare.



Participants at a Newcastle workshop.

Public dialogue findings

3. The context for genomics in healthcare

When participants reflected on the topic of genomics in healthcare, now and in the future, they raised key factors that influenced their thinking. These are described in this chapter and include reflections on how the NHS currently operates and also wider economic, social and political perspectives and what they feel these might mean, negatively and positively for the future of healthcare.

3.1 Genomics: potential to overburden a strained NHS

Initial discussions in the first weekend, encouraged participants to think about genomics and healthcare in the context of how the NHS currently operates and how it could operate in the future. For the 'now' discussion, many participants drew on their own experiences. A concern expressed by many was about the NHS straining to meet demand for its services and failing to deliver the care some people need (corridor care, decision making errors by overworked staff etc). Participants are worried that investing in genomics could take funding away from other parts of the NHS without fixing the fundamental issues the service faces. They fear that this will detract from the NHS's core aim of providing healthcare for everyone in society.

I understand there's a lot of pressure on where the investment goes within the NHS. But I think one thing we'll agree on is the NHS is incredibly underfunded in terms of the actual money that goes into the NHS. And therefore, are we channelling funds away from that into a different area, that isn't actually helping the basics of the NHS, which is again health for all. Which I think we'll all certainly say is the most important thing.

Participant, Newcastle

3.2 Potential for a longer-term paradigm shift: from reactive treatment to preventing ill health

These concerns about overburdening the NHS were raised alongside hopes for the future that genomics could be part of a complete pivot in the NHS from a treatment service to a prevention service. Many discussed the value of an integrated healthcare approach that combines genomic information with advice and guidance on nutrition, physical activity, wellbeing and other preventive measures that people can act on themselves.

There was just a feeling that preventative medicine is really, really the way to go for the whole population, and not just with genetics, but tying it into helping people with lifestyle illnesses. Because that's what people at my age start to see, your friends succumbing to stuff that they could have prevented. Whereas... If you actually say to somebody you are at greater risk of., you might be able to do that. That's more specific and possibly much easier to convey to people.

Participant, London

This is a complex picture for many participants who spent the dialogue weighing up the opportunities against the risks. They see the scientific developments in genomics and healthcare as positive and valuable, with it having enormous potential to provide valuable data to plan sustainably for a robust, preventive health system. At the same time, they also voiced the risk that the NHS is failing and, unless something fundamental is done to address this, the plan for genomics will not be effective.

On the one hand, I'm optimistic that there's talks about making the NHS more preventative and less reactionary, and I think something like this genome sequencing could really stack up data so that they can plan for longer-term futures and things like that. But on the other hand, my cynical-slash-realistic side can see (the NHS is) being cannibalised by private medicine, it's being underfunded by government, and it's a massive organisation that's resistant to change and adapt, and it's really at risk.

Participant, Newcastle

However, for many participants a focus on genomics in healthcare, as a pathway to prevention, is to be celebrated. They have high hopes for the research study and for the wider integration of genomic medicine in healthcare.

I think it's got great potential for preventive occurrences. To personalise medicine. I think it's got to be a good thing. You know, rather than one-size-fits-all. I'm, generally speaking, in short, positive about it.

Participant, London

3.3 Historic injustices, the current rise of right-wing ideologies and powerful elites

Frequently the discussions on the NHS drew on experiences of injustice and unfairness in the use of health and other data in wider public policy. This informed some participants' trust in a system which might use genomic and other health data. Some participants shared the example of the Windrush generation to illustrate this point.

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

Participant, Newcastle

Some participants said that the current political uncertainty and rise of right-wing ideologies in some countries, informs how they weigh up the opportunities and risks around a more concerted focus on genomics in healthcare.

None of this stuff happens in a vacuum, even in the UK. If you have a government which has increasingly racist rhetoric and then on the other hand you're giving it your DNA. How am I going to be like, 'Oh, the government wants my DNA, but they're also saying all of these horrendous things about people like me.' So how on earth is that going to marry up? People don't view the wonderful people doing this work as separate from these horrible things.

Participant, London

Some specifically raised how quickly the political climate in a country can change, and what effect that can have on approaches to healthcare. President Trump's second term in office in the United States was referred to in this context.

I suppose another thing that's a slight concern for me is political climate. Because we've seen how much Trump has dramatically changed America. And if we'd had a dramatic change in politics here, would the NHS still be there? That's a near immediate risk in reality as well.

Participant, Newcastle

A strong concern that genomic data could be used for profiling purposes was on participants' minds in this context. Some tied this to those with power, money and influence who they feel could use genomic data for illegitimate and illegal purposes, including eugenics and cloning, with no consequences or accountability.



Participants at a London workshop discuss public trust.

Two years ago, there was a channel for a documentary, about Jeffrey Epstein in 2017 investing a lot of money into anti-black and anti-racist eugenics projects to change the genetics of black people to make them smarter. That was only like 9 years ago, right?

Participant, London

This backdrop reinforced participants' desire for decisions made now by Genomics England about the research study, and decisions made by the NHS and the government about the use of genomics in healthcare, to be given strong, ethical and sustainable foundations. They do not want to see recurrent changes and shifts in politics here or in other countries affecting the potentially valuable use of genomics in healthcare.

4. Genomics and genetics in healthcare: associations and shifts in sentiment

The previous chapter explored the political and social context influencing participants' views on the future use of genomics in mainstream healthcare. This chapter looks at the associations in people's minds when they thought about genomics and healthcare. It also looks at how sentiment shifted from the start to the end of the deliberative process.

For many participants, genomics is both amazing and scary. Its potential to help people avoid or reduce the impact of health conditions, to better tailor medicines, reduce side effects and to supercharge research is hailed as hugely beneficial. At the same time, participants have deep concerns about their genomic data being accessed for non-healthcare purposes and widening health inequalities. During the dialogue process, participants' sentiment generally moved towards greater positivity, with a small number becoming more strongly negative. Many participants spoke about their ambitions for the UK to play a world-leading role in demonstrating how genomic data can be used to bring mass public health benefits whilst protecting the data and ensuring the environment changes to make healthy lifestyles attainable for all.

4.1 Genomics = amazing science/dystopian future and deterministic

At the start of the dialogue process and throughout, associations with genomics and healthcare were starkly polarised. Some participants sat at either end of a spectrum that spanned 'amazing' and 'scary', while

many held both views at once. What emerges from the discussions is a strong sense of an important responsibility to consider carefully the future uses of genomics in mainstream healthcare and its wider implications for humankind. Participants are conscious of the need to guard against potential harms, while not stifling progress for good. Some participants compare genomics health research to nuclear fission research, leading to the positive of 'clean, reliable' nuclear energy and the negative of the atomic bomb.

It's like pushing the frontiers of science in all ways... it's like the atomic bomb, isn't it? You discover it and you think you're doing good because it's energy, and then it's turned into a bomb somewhere down the line, you know what I mean? But does that mean that you don't pursue the research in the first place, because you don't know what's going to happen in 10 years' time?

Participant, Newcastle

Across the dialogue, participants spoke about genetics and genomics in health being 'black and white', 'more legit' and 'deterministic'. The combination of genomics and technology such as artificial intelligence (AI) is seen by some as a dynamic combination that could supercharge health discoveries, as this exchange between two participants in London illustrates:

Participant A: Maybe just there's a lack of knowledge overall around genes and what we're made of, so if we're told a certain piece of information which no one's ever told us, we're like, oh, damn, this is quite serious. You're more likely to be, OK, this seems a bit more legit. And now that we've got advanced technologies, it seems like things are more accurate, maybe.

Participant B: These genomic tests, your gene has so much authority and it's so deterministic. So even if you're told, yeah, you have a low risk of this ... it just sounds like so pre-encoded it would trump everything else that you're told and I guess it has to be communicated to you really carefully...in terms of other factors that can contribute.

Participant, London

Through the deliberative discussions exploring genomics in the context of other health factors in more detail, several participants re-assessed this 'deterministic' perception and said that they now came to see genomics as just another piece of health information to be considered, and no longer on a pedestal offering a higher truth.

I think what stuck with me is when you said it's a tool... It's just another thing that can be used to help me go towards the preventative side, instead of getting sick and then going to the hospital. So, if you see it that way, then it doesn't become a huge deal. It becomes another thing in the NHS world that is there for me.

Participant, London

4.2 Reasons to be hopeful: prevention, innovation, tailoring & planning

When sharing why they feel positive about the use of genomics in preventive healthcare, participants' responses ranged from the general, such as 'prevention is better than cure' and 'knowledge is power' to the more specific: understanding risk to help people prepare for a better future and tailored medicine is better medicine. Some recognise that new technologies can be met with scepticism, but hope this can be managed by exploring the potential positives.

I don't think that we should get bogged down in being negative. You know, years ago when they first started bringing out inoculations against smallpox or whatever, folk said 'oh that'll never work or that's not a good idea'. I think we've got to be open to the fact that science is improving all the time, discoveries are being made and goodness isn't it wonderful, some of this, that they can actually do that.

Participant, Newcastle

For many, genomics has the potential to be part of an NHS saviour story, helping the NHS to focus more on prevention and spend less on treating illness.

Even though the dialogue process focused on the use cases of pharmacogenomics (PGx) and actionable risk for specific prevalent conditions (CVD; cancer and dementia), participants spoke about other conditions that affect people they know. They hope that conditions such as multiple sclerosis, Ehlers-Danlos, autistic spectrum disorder and muscular dystrophies could benefit from the wider use of genomics in healthcare.

Family histories of health conditions were often shared during our discussions. Many are hopeful that genomics can help better understand family history and decode patterns of inheritance and other contributing factors.

4.3 Reasons to be fearful: data exploitation for non-health purposes, education divide and dystopian future

Participants' main fears centre on the sharing of data in ways that could harm individuals and families. Insurance companies, employers, police and immigration services having access to and using genomic data for non-healthcare purposes is seen as a redline. The question that hung over several conversations was: will the genomic data gathered for healthcare go on to be used for other purposes if the government of the day changes, or government policy changes?

Genomics benefiting 'educated people' and those with higher incomes more than anyone else was raised as a concern by several participants. What genomics can and cannot tell you about risk of health conditions, the interplay with other factors e.g. lifestyle and the environment and what to do with this information is seen as 'complex'. There is concern that wealthy and educated people will be able to make more use of genomic interventions, while the rest of the population are left behind, thus widening health inequalities.

It feels like it's a solution for more of an educated population... is that something for the middle classes, because it shouldn't be, but you know the assumption that it probably would be more for people who are more well-informed.

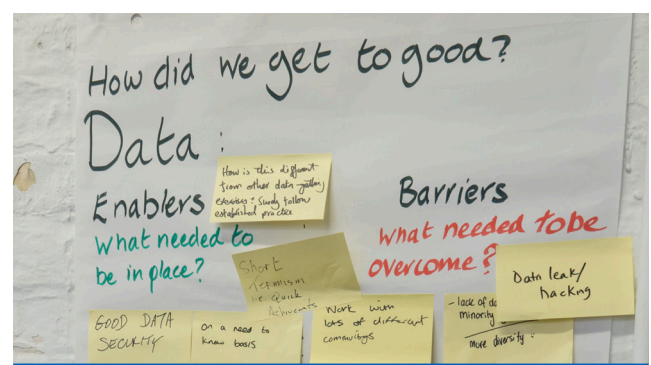
Participant, Newcastle

Fears about cloning, designer babies, eugenics, racism were mentioned at the start and throughout the dialogue process. Previous genetics-related scientific breakthroughs such as Dolly the sheep and Chinese scientists creating 'designer babies', as well as social media conspiracy theories of AI generated cloned celebrities were referenced in these conversations.

Well, there's the element of general education around genes, DNA, genomics, just not really being particularly prevalent. And I think that naturally brings a bit of scepticism towards it. Because when I first heard about this, my reaction was sort of sci-fi, sort of dystopian, but a bit kind of not normalised to a point where I went, ah, this is inherently safe, this is inherently something that I've got.

Participant, Newcastle

Overpopulation was raised by a few participants. They wondered whether breakthroughs in medicine, genomics included, could lead to people living much longer by preventing common killers such as cancer and heart disease, and in turn burden society in other ways and create new health challenges.



Participant discussion of data, enablers and barriers.

4.4 Questions around genomics

The questions that participants asked at the start and throughout the dialogue about genomics and healthcare reveal where there is uncertainty, curiosity, hope and concern.

They illustrate a landscape of attitudes and levels of knowledge that provides useful context for the design of the research study. The table below summarises the range of questions raised at the general level of genomics and healthcare.

Theme	Questions
Genomics & our health	Does our DNA stay the same or change during our lives?
	Can our environment change our DNA? e.g. smoking and cancer?
	How does our DNA interact with other health factors e.g. gut microbiome; inflammation?
	Which conditions can genomics help inform/diagnose/treat and which can it not: e.g. MS, bipolar disorder, muscular dystrophy, ADHD, autism...?
	Could genomics improve women's healthcare given historic gaps?
	Is gene therapy being implemented now?
Genomic data: Population	What is the 'reference gene' – how is it used? Given we come from such diverse backgrounds, what can it tell us?
	Why is there more genetic diversity in African populations vs the rest of the world?
	If you had e.g. a million DNA samples, why would you need more?
	What numbers do you need from different ethnic populations to make the data and learnings meaningful and applicable?
	What actions are being taken to redress lack of diverse ancestry in genomic data?
Genomic data: Personal	Will my whole genome sequence be looked at or just specific genes? Who will know what about my genomics? What will I know?
Progress & priorities	How did Covid-19 change genomics research? What other genomic research has taken place since Covid?
	How is it decided which conditions are looked at through a genomics lens? How is what gets researched prioritised? Who decides? Based on what?
Landscape & who's involved in this space	Can I do this (PGx and genetic risk information) privately now?
	What links does this proposed research study or Genomics England more generally have with Our Future Health?
	Is there co-operation with other countries, the World Health Organisation, to share data and findings?

Theme	Questions
Family	If you have a genetic risk finding, will it also appear on other family member records e.g. father, aunt, cousin?
	Will a whole family be sequenced or just adults (in the research study)?
	Will it tell us why some in the family have allergies and health conditions and why others don't?
	What does it mean to 'skip a generation'?
	How good is family history at determining risk of health conditions? Will whole genome sequencing tell us much more? Will it be worth the cost?

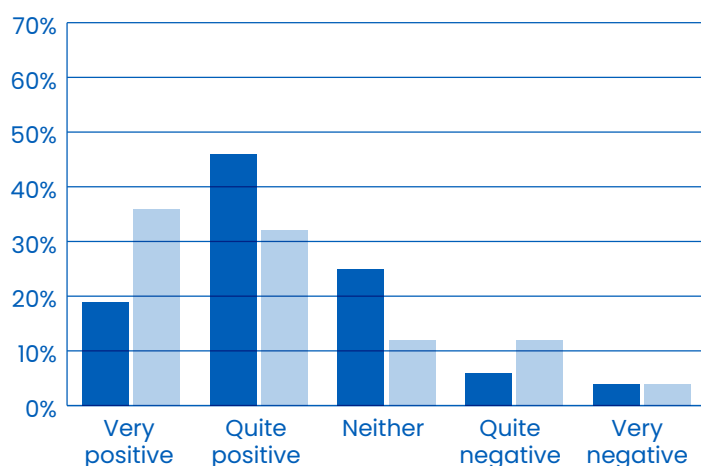
4.5 Participant journey: deepened views, some more positive, a few more negative

At the beginning of the first dialogue workshop and at the end of the final workshop, the visual voting tool Mentimeter was used to ask these two questions:

1 When you think about the future of healthcare and the role of genetics / genomics in preventive medicine, are you: Very Positive / Quite Positive / Neither / Quite Negative / Very Negative

2 Please say why

How views changed over time
South East (London)

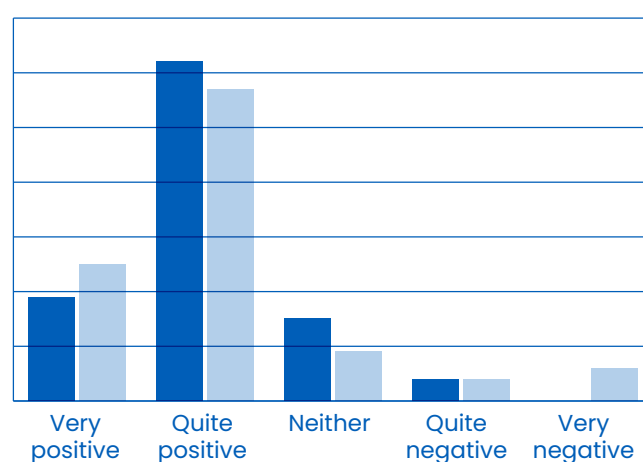


Whilst responses cannot be tracked from specific individuals (gender/age etc), a pattern can be seen for how views changed or stayed the same and why.

Positive sentiment substantially outweighed negative sentiment. When the "quite" and "very" responses are combined, around two thirds to three quarters of participants described themselves as positive about the role of genetics and genomics in preventive medicine. That said, the qualitative reasons people gave for their answers make clear that "positive" rarely meant uncritical. The dominant pattern is conditional optimism: participants welcome the potential benefits in principle while carrying significant concerns about data governance, equity of access, NHS capacity, and risk of misuse.

■ Workshop 1 ■ Workshop 4

North East (Newcastle)



In both locations, the proportion choosing “very positive” grew between the first and fourth workshops, but so did the proportion choosing “quite negative” or “very negative.” The middle ground – “neither” – shrank.

Among the London participants, the shift towards stronger views in both directions as pronounced. By Workshop 4, a notable cluster of participants had become more firmly positive; several explicitly linking this to having received more information across the programme (“I feel more informed now and can see more positives than negatives”; “my questions have been answered”). Among those selecting “quite negative” or “very negative”, some cited distrust of government data management; another named ‘exploitation by pharmaceutical and private companies’, lack of NHS funding, and questions of informed consent.

Among the Newcastle participants, the overall mood was somewhat more stable. The “quite positive” majority held across both workshops, though a small, very negative group appeared by Workshop 4 that had not been present in Workshop 1. The reasons here reflected similar concerns to the London participants, but with a slightly greater emphasis on implementation; NHS digital infrastructure, timelines for rollout, and whether the technology would actually deliver.

The overall trajectory across the dialogue process suggests that deliberation deepened rather than simply shifted views. People moved from initial curiosity or uncertainty towards more formed positions, and those formed positions were spread across the scale, not uniformly more positive.

Small group discussion at a London workshop.



5. Pharmacogenomics (PGX)

There is broad understanding of and support for pharmacogenomics, because participants can see its potential to address a range of genuine problems in healthcare which resonate with their lived experiences. The suffering caused by a trial-and-error approach to medicines, having to tolerate sometimes serious reactions and side effects, and issues around inefficiencies and medical waste.

Participants' concerns centred around PGx contributing to a focus on pharmaceutical solutions at the expense of more holistic, lifestyle based or systemic approaches. These concerns related above all to the rollout of PGx in mainstream healthcare; few concerns surfaced in relation to PGx as part of the research study, and participants could see many potential benefits arising from PGx research contributing to clinical evidence.

How PGx was explored in the public dialogue process

Information about PGx was shared with participants in case studies, expert speaker

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.

presentations and panel discussions. Participants were introduced to the fundamentals of PGx, including how and why some medications do or do not work, areas of certainty or debate, how PGx is currently used in the NHS and how it could be used in the future, including its role in the research study. Three medicines were chosen as stimuli to explore attitudes: statins for high cholesterol, anti-depressants (SSRI)s and the mini-stroke treatment clopidogrel (see Technical Appendix for the case studies used). Through these formats, participants heard a range of views on the utility and impact of PGx.

5.1 Questions about PGx

This table summarises questions about PGx which emerged during the course of the dialogue. Associated themes are explored further in the findings below.

Theme	Questions
Pharmacogenomics	Why are so few drug-gene pairings currently being used in healthcare? How much and how quickly will this evolve? Implications for cost-benefit of PGx?
	How are drug-gene pairings chosen for research or inclusion in healthcare? Severity of side effects? Prevalence of condition? Widespread use of medication?
	How accurate are PGx findings? How much detail will exist about side effects? How will findings be kept up to date?
	How will PGx findings affect drug production, cost and availability?
	How long will testing take compared to trial and error?

5.2 Benefits of PGx

The benefits of PGx feel straightforward, objective and tangible

Many participants could easily grasp the benefits of being prescribed medication which suits them better, thereby avoiding unnecessary side effects, trial and error or ineffective treatments. Several participants described PGx data as objective and practical information that could improve outcomes immediately.

Pharmacogenetics is relatively new, so it interests me. But again, it's factual. I like facts, I like to know that I can't take this because of that. So, this is going to work 10 times better. And we're going to give it to you because it's only 2 times more expensive than the drug that we're originally going to give you because that will be a factor as well.

Participant, Newcastle

Less trial-and-error; better health outcomes more quickly

Through lived experience of ill health or caring for friends and family, many participants are very aware of the physical and psychological distress caused by a trial-and-error approach. Many described the time wasted coming on and off different medications, the feelings of being a 'guinea pig' and the uncertainty around the best treatments as compounding illness and vulnerability.

By potentially guiding HCPs and patients to the right medication and the right dosage first time, many participants see PGx as addressing a genuine and serious problem in their experience of healthcare. Several participants said that in this way PGx would build trust in the health service and in patient-HCP relationships.

Improving trust, because if you've been on lots of different drug regimes and they've not worked, your trust is going to be lowered. So the next time they say, well, try this new one, it might work. And you think, oh, here we go again.

Participant, London

Fewer side effects

Participants were struck by information provided about high rates of hospitalisation and the costs to the health service associated with dealing with side effects of medication. These figures nonetheless resonated with their lived experience or awareness of prevalent and severe drug side effects or reactions, which they explained can sometimes be worse than the original condition.

I haven't had to take time off work because of the illness, I've had to take time off work because of the reaction to the tablet. I couldn't function, I couldn't clean, couldn't garden, couldn't take the dogs for a walk, couldn't do a thing. They wanted me to trial that for two months, I said no, it's worse than the symptoms.

Participant, Newcastle

In particular, participants spoke about the seriousness of side effects for mental health medications, widespread intolerance to blood pressure medications, and the gruelling effects of cancer treatments coupled with uncertainties about effectiveness. Many could immediately see the benefits of PGx tailoring treatments to prevent side effects and improve effectiveness.

Small group discussion at a London workshop.



At the minute, particularly with cancer drugs, I think it's a lot of it is hit and miss. If you have a high percentage chance of not having these side effects or having treatment that works, then we were very much up for that as opposed to the current system where you might have six months of a treatment that doesn't work and then you get very ill from it. If you could bypass all that then that improves the quality of life for everybody, doesn't it?

Participant, Newcastle

Many participants also expressed concern about the health impacts of taking multiple medications to counteract side effects, and how PGx has the potential to reduce volumes of medication taken.

Seeing my mother, who's 90, take medication to counteract the side effects of medication, she rattles when she walks, she takes so many tablets. And if we could tailor it down to just one or two, that's perfect from the pharmacist's point of view. It's certainly from a disease side of things.

Participant, Newcastle

Several participants described anxiety about side effects preventing them from taking medication, and how PGx could provide reassurance about what they are prescribed.

I like the idea of it because I'm really anxious about taking new medicines and sometimes I've been prescribed things and then not actually taking them because I'm so worried. I'm more worried about having a reaction to it than I am about being ill. And my GPs don't know that I've done that because I'm too ashamed to tell them. So I'm sort of thinking, I would be so reassured, because my mum also has had lots of reactions to different medicines, so some of it might be genetic.

Participant, Newcastle

Improved medication adherence

Many participants described scenarios where they or people they know of had stopped a course of treatment due to the severity of side effects or the perceived ineffectiveness of medication, often without speaking to an HCP. They hope that PGx could identify appropriate treatments more quickly, and provide more confident and tailored dosage information to encourage adherence and prevent the risk of potentially serious consequences of patients giving up on treatment.

A lot of people will go, "Yeah I'll take the medication, oh I feel rubbish on it", and then they don't even bother going back to their GP and saying it doesn't work, they just stop taking it.

Participant, London

Decreasing medical waste

The scale of medical waste in the health service is something many participants find problematic. They attribute it to a multitude of factors: overprescription; patients not taking or finishing their medications; unsuitable medications; a build-up of repeat prescriptions in the absence of regular review, and medications being prescribed to counteract side effects. Participants can see the potential of PGx reducing medical waste by addressing the causes directly.

I feel like it would cut down maybe the volume of drugs that people take, because I have taken a lot of different drugs, because I've got lots of different health conditions, and I don't even know what works and what don't work, because there's so many.

Participant, London

Saving the NHS (and patients) time and money

A recurrent theme throughout the dialogue was the resource strain the NHS is under, coupled with inefficiencies participants have witnessed in the health system. Many spoke about the preventive potential of PGx

improving efficiency, in relation to patients receiving and adhering to appropriate treatments.

You mention statins... they are expensive, but they're a fraction of the cost of having a heart attack and going into hospital ... primary care is always cheaper than secondary care, secondary care is massive amounts of money.

Participant, Newcastle

Several participants also spoke about the potential of PGx saving HCPs time by providing them with accurate guidance from the outset.

A positive which stood out for me is they've got the information at their fingertips. He's gone to the doctor, and they already know, right, okay, drug A isn't suitable, you're going to get multiple pains. So, it's kind of the fact-finding's already done.

Participant, London

A few participants also mentioned spending less money on prescriptions if they got the right one first time.

With trial and error, every time you try something, and it doesn't work, on top of that you have to pay for prescription as well.

Participant, London

Personal access to PGx data could empower patients

Many participants spoke about the potential to take better control of their own care if they have access to their PGx data. Some participants who had experienced discrimination in the health service as a result of their ethnicity or gender, feel that PGx could be a useful tool for them to advocate for their needs, as it provides objective evidence which cannot be easily dismissed.

If you have your own information, you can use it. I've experienced a lot with my parents, where a lot of people stereotype them. So they would just automatically dismiss certain things just because of our ethnicity or where we come from. They're like, oh, it's because of the food that you have. Or it's because of the way your lifestyle is, that kind of stuff. If they are going to give me something, then explain the reason behind it. Because right now, they don't have to explain. I could be like, can you explain to me why I might be experiencing this? Is it because of something like this on the app?

Participant, London

PGx could lead to improved personalised medication in the future

Participants are optimistic about the potential for PGx to contribute new insights to clinical evidence which could lead to developing novel or improved medications. Some spoke about under-researched areas such as women's health, where there may be less availability of targeted medication, for breastfeeding mothers for example, or more uncertainty around drug effectiveness. They hope that PGx could begin to shed light on why some medications work for some people and not others and inform new drugs.

They basically said, because you're breastfeeding, there's no pain relief you can have apart from a bit of paracetamol. It's not gonna cut it for a broken knee and a broken spine and ribs, is it? I had to have nothing and just deal with pain because I wanted to breastfeed my child. But that's because according to them, there aren't any available medications that can work for women who are breastfeeding. And I feel like a lot of women in general's pain is minimised by the NHS, unfortunately, because a lot of these things are made by men.

Participant, London

A few participants spoke specifically about the possibility of PGx being used to inform the pharmaceutical industry of where new formulations are needed.

If drug producers know they can bank on the NHS to look into pharmacogenomics more, they'll be more incentivised to actually deliver drugs that we don't have right now that will help people, people that obviously don't react well to the ones they've got.

Participant, London

One participant spoke about the potential for PGx to inform broader public health initiatives such as food fortification, as some people are unable to convert certain vitamins and minerals into what their body needs.

More awareness and discussion of drug reactions and interactions

There is broad agreement that PGx findings could lead to more discussion, explanation and understanding of varying reactions to drugs in the context of consultations and also in society more widely. Some participants said PGx could also open the door to more understanding of drug interactions or contraindications and hopefully lead to a reduction in the volume of medications prescribed to individuals. A few participants said PGx may enable people to plan better for the future and take preventive action if they know certain medications may not be effective for them.



5.3 Concerns about PGx

PGx rollout could put greater onus on pharmaceutical solutions at the expense of lifestyle, structural or holistic approaches

Many participants feel that the NHS often over-medicates patients, sometimes as a reaction to time and resource constraints. There is concern amongst participants that PGx data could contribute to this “quick fix – drug first” culture, particularly by time poor GPs. They fear medications will be the immediate response, rather than giving consideration to wider factors contributing to ill health, or more lifestyle-based solutions.

Doctors are overburdened at the moment, GPs and hospital clinicians, there is always the risk of taking the easy option and the easy option genetically says this drug will work (...) you forget about the potential for socialisation, therapy, and lifestyle changes. They are more difficult to implement, but equally effective if they're properly managed. There's a danger of taking the easy route.

Participant, Newcastle

PGx further over-medicalising mental health is of particular concern

The need for a nuanced approach to mental health is something many participants spoke about. Lifestyle factors and talking therapies can be an essential part of treatment, alongside or instead of medication.

Participants described their lived experiences of over-prescription in mental health services in a context where appointments are short, waiting lists for therapy are long, and lifestyle interventions may not be available. Many are concerned about PGx contributing to a drugs first approach in mental health. They feel that PGx does not necessarily sit comfortably in an area of health which is so complex, multi-factorial, subjective and where so much is still unknown.

It's not like blood pressure lowering, where you've got a hard end point, mental health is quite subjective to how that person feels and what is better for them, what better means.

Participant, Newcastle

PGx could be deterministic and undermine patient agency

Participants understood PGx data to be quantifiable evidence about drug interactions with their genes; a part of them which doesn't change. This brought with it concerns that PGx findings could be treated as categorical by HCPs and take precedence over lived experience or more nuanced or holistic pathways.

You might be listened to less. Does it say, it's written in your genes, that's what you have to do?

Participant, Newcastle

Some spoke about their concerns around HCPs throughout the NHS being adequately trained to use PGx data appropriately.

If you've got a GP who isn't confident or happy to use it, that's a problem in itself. If you haven't trained up your GPs across the country to know exactly what to do and how to use the data, then what would be the point of you volunteering your data in the first place?

Participant, London

Some participants feel concerned about the possibility of PGx putting more power in the hands of the health service at the expense of patients, and the possibility of HCPs refusing treatments or dissuading patients from taking certain medications. Some spoke about wanting to be able to make their own choices and trade-offs about tolerance of possible side effects based on what is important to them as individuals, considering their experiences and lifestyles, and other drug or dietary interactions.

If, for example, I was feeling really down and suicidal, if the reaction is I'm going to have an upset stomach for half a day, but I'm going to feel right as rain the next day, then having an upset stomach is actually an acceptable situation.

Participant, Newcastle

PGx could affect patient care, as could opting out

As well as concerns around HCPs focussing on the presumed certainty of PGx data, some participants are concerned PGx could contribute to further automation of prescribing, and erode face-to-face contact more generally.

There is broad agreement that patients should be able to opt out of pharmacogenomic testing. However, some participants are concerned about the implications of opting out if PGx becomes part of mainstream health, and whether this could negatively affect patient care.

If you have that opt out, does it create a two-level system, so the people who are opted in get better treatment or faster treatment than the people who have opted out?

Participant, Newcastle

Will alternative medications be available, effective and appealing?

Across several groups participants discussed what might happen if a particular medication is refused or not recommended to a patient as a result of their PGx data. There are concerns around suitable alternatives being provided, and the availability of those alternatives if certain medications are found to be unsuitable for large numbers of people. Participants raised concerns around less effective medicines being developed or prescribed with the aim of avoiding side effects, and possible frustrations around being prescribed a less than optimal drug, or a lower dose than they were expecting.

If a medication is denied, then what's the alternative option? You can't just be like, there's nothing we can do for you, so then they need to have some sort of back-up because we can't take the best medication.

Participant, London

The cost-benefit of PGx in mainstream healthcare needs careful consideration

Discussions often gravitated towards the balance between the potentially high costs of introducing PGx in mainstream healthcare – from testing to data storage to communications and delivery – and the benefits to the public and the NHS. Having heard about the small number of gene-drug pairings currently being used in the NHS, participants questioned how many people in society would actually benefit from it. This led to some participants questioning whether society-wide lifestyle interventions could be more cost effective.

It comes down to what would be the best use of public funds. And that needs to be decided upon. Would research to get people healthier, would that have more impact than... effectively doing a test where 5% of the population would have a negative impact of drugs?

Participant, Newcastle

Some participants also had questions around levels and probabilities of side effects PGx is concerned with, and whether this is worth the cost. For example, whether the aim is to prevent patients experiencing mild side effects as well as serious ones, or preventing side effects even when probabilities are low.

There may be certain drugs which maybe have certain side effects but they're not brutal. I mean, if one drug costs five times more than the other and had slightly fewer side effects, how should these things be worked through?

Participant, Newcastle

Some participants pointed out that currently the cheapest medications tend to be prescribed first. They are concerned about the cost implications of being recommended potentially more expensive medications as a result of PGx, either to the NHS as a whole, or to individual patients who pay for their prescriptions.

Mistrust of pharmaceutical companies brings concerns about how profit motives could play a part in PGx rollout

Across both locations, many participants shared concerns about pharmaceutical companies using PGx data to sell more medications, which could contribute to more emphasis on drug-based solutions in the health service and wider society.

This is going to profit pharmaceutical companies much more. Instead of a healthier lifestyle, they're going to push more drugs into society.

Participant London

Specifically, some participants are concerned that if pharmaceutical companies have access to data about particular drugs being more or less suitable for particular groups of people, they could adjust their pricing accordingly to maximise their profits. This cost could be passed on to the NHS or to individual patients.

In terms of health care reps and going around and influencing GPs ... I mean can you see pharmaceutical companies pushing certain types of drugs because they're going to work with genomes of a certain type.

Participant, Newcastle

5.4 PGx implementation

PGx findings should be available to HCPs across the NHS

Participants broadly agree that the ideal scenario is a centralised system where their PGx data is immediately available to HCPs across the NHS, including GP surgeries, hospitals and pharmacies. They feel this could enable prescribing decisions to be made quickly and safely in any scenario, including emergencies.

However, participants frequently spoke about the challenges of the current disjointed nature of NHS health data. Some hope that the use of PGx data could encourage or contribute to centralising and standardising how health data is stored and shared across the NHS.

Participant A:

When I was young, I developed bronchitis, and I'm severely allergic to penicillin. I was near death, so it became a red flag on the front of my medical record, but that did not translate over to the digital record. So I had to inform the GP, and then moving GPs that didn't transfer across to another GP practice. So there has to be a 'backbone', something 'back office', that has all this PGx information on it to inform everybody that would potentially prescribe medication. So pharmacy, GP, healthcare providers, et cetera.

Participant B:

That's what I was saying about all these systems that don't talk to each other.

Participants, Newcastle

Pharmacies will have an important role to play when PGx is part of mainstream healthcare

Many participants said they value the expertise of pharmacists and are aware of efforts the NHS is making to encourage the public to use pharmacies for common health conditions. Some suggested pharmacists may have more time and possibly more expertise

than GPs to discuss PGx based prescriptions, and they could provide valuable advice or a second perspective. However, a few participants raised concerns about health data being shared with pharmacies, which they see as separate commercial entities that may not have the same level of data protection or accountability as the NHS.

Participants want PGx data integrated into their health records for use at relevant times, but personal access is a matter of choice

There is no consensus over whether or how PGx data should be made available to research study participants, or the general public in the future. Participants suggested that personal preference should be recorded when samples are taken.

Many participants feel that PGx data can go straight to their health records rather than being available to them personally through the NHS App. They said they would only want to hear about relevant drug interactions alongside an explanation from an HCP at the point of being prescribed medication. They are concerned about too much information being provided which could overwhelm or confuse people, or take up NHS time and resources unnecessarily if people request explanations from HCPs which may never be needed.

I feel like it should be a preference. You could always choose to see that information, but I don't personally feel like I would like to know any of that info. Just because I would overthink or be anxious about choosing the medication for myself and then talking to a GP about it. I'd rather my GP talk about it first and go through the options.

Participant, Newcastle

Many other participants said they would like to have access to simple PGx data in layperson's terms, on the NHS App, as soon as it becomes available. Currently the number of known drug interactions is small, and they feel the amount of information for any individual would be useful and manageable. Some participants explained they would be comfortable

receiving PGx data in this way because it is not diagnostic or sensitive; it relates to medication rather than conditions specific to an individual.

It's less loaded information, and therefore even if I can't comprehend it or it doesn't feel relevant in this moment, I'm fine to have that statement in my NHS App. It's not like I'm going to be worried about getting a notification to tell me my results have arrived. It doesn't inherently mean something's wrong with me, it's just if I need that information, it's there. It's not going to bother me on that level until it's needed. Have it up next to your medicine cabinet.

Participant, Newcastle

Some participants explained that personal access would allow them to advocate for themselves or loved ones, in a context where HCPs are under time pressures and NHS IT systems struggle to communicate with each other. Some also said they would like the option of being able to access even more detailed information on request. Several participants spoke about how useful it would be to have their PGx data available for use outside the UK when they travel.

I like knowing all my information, to be honest. If they had access to it, I'd be like, yeah, can I have it? Even like blood results, I sometimes go 'can I just get a printout, please?' Just so I've got records in case anything happens in the future, or that I've got access. Because you know how long it can take sometimes, trying to get someone to just give you something.

Participant, London

Whether people receive PGx findings via the NHS App, or at the point of being prescribed relevant medication, there is broad agreement that clear communication about the genetic component of the findings is necessary. Many participants described scenarios where they

couldn't question why they may be provided with a different medication or dose to friends or family with the same condition. It is important to know why that may happen, and why a prescription has been recommended, particularly for groups of people who may have lower trust in the health service.

Patients should have a say in PGx-based prescription decisions

At the point where a prescribing decision needs to be made using PGx, many participants feel patients should have the opportunity to discuss options with an HCP. They want to understand the choice being made, and have a say in any trade-offs between treatments, outcomes and side-effects. Different symptoms or side effects may be more or less significant or bearable for different people.

There might be certain side effects that are contained in each drug that are more desirable to each person to avoid, so for example you're a particularly active person and this drug causes muscle spasms, or there's one that causes a brain fog or something like that.

Participant, Newcastle

Many participants also emphasise the importance of communicating levels of uncertainty clearly to inform their choices. Some participants said that PGx data is still useful where there is uncertainty, as the starting point is likely to be an absence of data, so even uncertain PGx findings provide useful guidance.

I guess even though it's still not 100% certain you're not going to have muscle strain or whatever, it's at least more than if you didn't have that genetic testing and you just wouldn't have any idea about that whereas this one's like okay you've got 60% chance, that's better than not knowing anything.

Participant, London

Several participants also suggested that it would be useful to have a formalised way of providing feedback about their experiences of medication efficacy and side effects, to further inform PGx based medicine.

I wonder if there'd be any way of feeding back into that, if you are getting symptoms of medication, we talk about having targeted medication, but actually is it an opportunity where the people taking them sort of say well actually this is happening to me, so we're getting a much better idea.

Participant, Newcastle

A few participants sounded a note of caution about the importance of not overpromising a bespoke approach to medicine, as PGx only covers a limited number of medications and conditions, and does not involve treatments being designed for individuals.

We know there will be groups of people who, because of their genes, won't react positively to conventional, cheap medicine that we have now. Great, in the future we might be able to look after you better, but this idea that we're going to have personalised, tailored medication for everyone, I think they should be careful with overselling people on this whole idea.

Participant, London

PGx is one tool among many

Although the immediate benefits of PGx are clear to many participants, there is broad agreement that PGx findings must not eclipse other information about a patient, or lead to a focus on medical solutions when there is a role for lifestyle interventions. PGx data should ideally be treated as one tool among many which forms part of a holistic approach to people's health.

There's something about balancing the information that we get from genetics with all the other factors. It's factual clinical data. What about environmental, circumstantial, lived experience. It's only one point of data.

Participant, Newcastle

Many participants are also keen to emphasise wider systemic factors and population-level health interventions around lifestyle, which could potentially have a greater impact on a greater number of people than PGx. Some said this wider perspective should inform funding decisions around genomics in mainstream healthcare.



London participants in discussion with an expert speaker in a workshop.

6. Actionable risk

The potential to use genomics, alongside other health factors, to help understand and guide actions to prevent or reduce the impact of future illnesses is welcomed as a concept.

However, as the dialogue process progressed, and participants learnt more about types of genomic risk information (polygenic and monogenic), and the evidence base, participants developed their expectations. These include:

- Ensuring that risk information is combined with clear and personalised guidance;
- There is choice over what risk information to receive;
- The evidence base is strong;
- The use of genomics in healthcare is accessible to all, not just the wealthy and educated.

There is also the expectation that genomics will not be treated as a ‘silver bullet’ for better health. Participants want to see actions to create an environment where healthier food and physical activity is more accessible for all.

How actionable risk was explored in the public dialogue process

Information about actionable risk was shared with participants in the following forms: scenarios, expert speaker presentations and panel discussions. Three health conditions were chosen to explore attitudes: cardiovascular disease (heart disease), dementia and cancer. The heart disease and dementia case studies included both monogenic and polygenic risk scores. The cancer case study focused on monogenic (e.g. Lynch syndrome). These conditions and the role of genomic risk were also explored more broadly in the expert speaker presentations and through the panel discussions. Through these formats, participants heard a range of views on the utility and impact of risk scores, particularly PRS.

6.1 Risk vs diagnosis: high risk feels like a diagnosis

Genomic risk, rather than genetic diagnosis, is a tricky combination. Genetics is seen as the essence of who a person is and something that is fixed for a lifetime. It is associated with certainty and determinism. It can therefore transform the perception of ‘risk’ or ‘chance’ of a health condition into what feels like a diagnosis that hasn’t happened yet.

We’ve kind of thought, high risk, finding out the term high risk, it’s almost like giving someone a diagnosis.

Participant, Newcastle

When combined with the current experience of almost all NHS interactions being about diagnosis and treatment, the introduction of genomic risk information feels like a big shift in people’s relationship with the NHS. It changes what people know about their own and their family’s future health.

It also changes what is expected of people – from seeking treatment for existing health conditions, to more onus on people to prevent them. The integration of genomics into an understanding of health risks leads to expectations for highly personalised information in return, combined with more tailored guidance about how to prevent future illness.

This chapter of the report will explore how participants wrestled with the positive of prevention being better than cure, alongside concerns of creating a nation of ‘patients in waiting’ living under a cloud of potential health conditions and adding burden to the NHS.

6.2 Hopes for actionable risk genomic information

Prevention is better than cure

The overarching positive for the implementation of genomics as part of actionable risk information shared for preventive healthcare was often referred to in shorthand with the adage 'prevention is better than cure'. This section explores the potential benefits participants identified for individuals, society and the NHS.

The idea that you could do something to change, in terms of the future plan, to be able to change your lifestyle or the way that you manage how you are as a person, to try and mitigate anything that might be coming down the line.

Participant, Newcastle

Individual benefits of actionable risk information: forewarned is forearmed for a healthier life

For individuals, the positives focus on living healthier for longer by being able to do something ahead of time about potential health issues. Many spoke about being on the front foot of preventing, rather than the back foot of treating illness. They hope to change the predominant discourse in everyday conversation from discussing ailments to talking about actions to stay well.

I do think if we go down this route, people will be a lot more health conscious, just because it's part of everyday conversation. Because they'd be told a lot earlier on, oh, this is something to look out for.

Participant, London

Planning for the future, beyond healthcare decisions, is seen as a benefit by some. For example, awareness of a higher risk for dementia in a family might mean they have the opportunity to plan ahead, such as organising power of attorney.

It's about the same as what makes a good manager. And so, managing your own health in terms of sort of managing a company, to be a good manager, you predict the future and plan for it. If you've got any tools that can help you predict the future, you can then plan for it.

Participant, London W2

Some participants hope that genomic health data could lead to more personalised and tailored approaches such as the timing and frequency of health screening.

So maybe once that data is analysed, they can decide that early intervention, early screening is perhaps necessary. So, they invite me for a screening for bowel cancer or whatever and when I'm sitting there, they tell me..., oh the reason we brought you in is because based on that genetic test we've detected that you might be at high risk that's why we brought you in early and...then I kind of feel reassured as a patient thinking, okay they're looking after me.

Participant, London

Interest in actionable risk among some people with a family history of health conditions, such as dementia, heart disease and arthritis, is strongly positive – it offers a chance to understand and prepare for potential conditions that have affected a family. While others, with and without a family history, are uncomfortable with the prospect of receiving what they see as negative information (e.g. high risk).

Other ways that individuals could benefit from genomic health data included contributing to future health research and innovation, and providing more health insights to people separated from their birth parents and families.

Benefits for society and the NHS: a shift from illness to prevention – but is this achievable?

For wider society and the NHS, participants are cautiously hopeful that taking a more holistic, preventive approach to health will benefit society. However, they worry that the resources needed to produce and share personalised health information and support health behaviours may not be available in the NHS.

So, in order to make it actually impact correctly and be worthwhile, it is a bit more necessary to look at it holistically, but then how much are they able to do that? That's kind of what I was thinking with the time constraints and the money constraints of the NHS.

Participant, Newcastle

Sharing actionable risk information has a long-term benefit of reducing the costs of treating conditions such as cancer, heart disease and also diabetes. The money saved could be re-allocated to other health needs, such as prevention, for example funding discounted gym membership and mental health support. That said, few participants see genomics as a silver bullet to reduce NHS costs in the short or medium term.

There is a sense of being in the early stages, or the foothills, of using genomic information to improve population health and that the decisions made and actions taken today will be most beneficial to generations to come.

My hope was better outcomes for healthcare in the future, not just now but like a generation from now, two generations. Even though this research is going to benefit us now, like in ten years, I'm thinking of the generations to come, that's where I feel it will really make an impact.

Participant, London

6.3 Concerns

Context for concerns: genetics – from gospel to fortune teller

'Black and white', 'gospel', 'definite', 'authority', 'deterministic'; these are among the words participants used to describe their understanding of genetics and genomics in the context of health at the start of the process.

Participants talked about the tension created by the societal perception of genetic determinism and the fact that your genetic profile is fixed over your lifetime versus what genomics can, might or can't tell us about our health.

Genomics as another layer of information rather than giving you a yes-no answer, but because it feels like it has so much authority, you want a yes or no answer, but it can't give that to you...It's just another factor that you need to consider when you're considering your risk. But I feel like if it's like genetics-based, it has more weight, because your genes are kind of set, basically, because you can't do anything about genes.

Participant, London

This shift in views from 'gospel' to 'part of the jigsaw puzzle' was influenced by a range of information including:

- The varied impact that genetics has on health, for example single gene conditions (rarer e.g. Huntington's disease, cystic fibrosis and sickle cell) and multifactorial conditions (more common e.g. CVD; cancer, dementia);
- The evidence base for PRS and the incidence of false positives and false negatives in comparison to the number detected who go on to develop the health condition;

- Alternative interventions to mass genomic sequencing / actionable risk sharing: such as prescribing statins to everyone over 50 to reduce ill health and deaths from CVD.

The rest of this section explores participant concerns around data reliability, consistency and complexity. It looks at the impact on individuals and society; anxiety, ability to act and implications for family. Finally, it explores concerns around resources and the potential overburden on the NHS and staff.

Data reliability, consistency & complexity

The fact that most genomic data and its findings come from people of white, European ancestry causes many participants to question whether risk information will be more reliable and accurate for some than others. This was felt to be unfair and held the risk of widening health inequalities.

My concern, because it's in its infancy, is the data representative enough and accurate enough to be meaningful? It's all well and good giving this genetic test, but it's for a different ethnic group, so it's less relevant.

Participant, London

Questions were also asked about whether HCPs would interpret and share risk information inconsistently or may choose to withhold some risk information from you.

They would effectively be, in effect, playing God. "I'm going to decide whether to give this person this life-changing information or not and how" ... is it going to be based on prejudice or is it going to be based on my personal knowledge or attitude towards genomic studies. I might be sceptical... a hell of a lot of importance being placed on "me as a GP".

Participant, London

Risk information, its interpretation and impact are seen as a minefield for communication: absolute and relative risk, percentages, interaction of lifestyle factors all create confusion and cause unpredictable responses from individuals.

Impact on individuals and society: anxiety and only benefiting educated, well-off people

Sharing a risk of developing a future health condition which has a genetic component may cause considerable and damaging anxiety in the recipient. This was a recurring concern throughout the dialogue. The impacts on the individual were seen as emotional and practical:

- The stress of living under a "sword of Damocles" – affecting people's mental health and limiting their life choices;
- A higher risk score: if people have no symptoms, they may ignore risk information because they have so much else going on in their lives which has a more immediate impact for example raising children, managing existing health issues, juggling work demands;
- A lower risk score: could lead to reckless behaviour, for example can eat and drink what I like without any consequences;
- Discrimination: if you chose not to have a genomic risk profile, you could experience a second-class NHS;
- Discrimination: if you chose to have a genomic risk profile, and receive a high-risk score, you "aren't worth it (treatment) anymore";
- Increasing travel and health insurance costs;
- Employer access to risk information, limiting job options;
- Exposing questions about parentage.

I just feel like anything can happen. I'm not worried until it happens. I'm just kind of enjoying my life, dealing with the stresses of life as it is, dealing with the minor health issues that I'm dealing with now... And I just think, I know for a fact that anything can happen at any moment. Why would I then go and look for it, you know, and find it?

Participant, London

It was emphasised during the dialogue that Genomics England plans to only share risk alongside actions. These actions could be about how to maintain a low risk or to mitigate/manage higher risk. Participants spoke about the 'actionability' of risk information being essential to reduce or manage anxiety.

I think the actionability part of it is the important part. It's all well and good saying you have this, that or the other score, but people want to know what that means and what to do next. You know, it's like your risk score is 6.7, this is what you need to do next.

Participant, London

However, several participants questioned the personalisation and accessibility of the actions. They wondered whether the actions would simply be the already familiar and generic health messages of 'eat healthily and exercise more'. Genetic, personalised risk information carries with it expectations that the health advice would be more detailed and personalised to them.

A connected concern is that the risk information and associated recommendations might only be understood and acted on by well-educated people on higher incomes. They expressed the worry that the invitation to take part in the research study, or service if rolled out, as well as the information returned, might be too complex for some to grasp or would be ignored by those living busy, stressful lives.

In both locations, participants spoke about receiving advice that isn't actionable in the current environment, particularly for those on lower incomes. The cost of healthy food, the prevalence of unhealthy food, the life stresses people have of working long hours and caring for family members, are barriers to the lifestyle changes that may be necessary to reduce risk.

Meanwhile, those on higher incomes would have better access to healthy lifestyle choices and be able to afford the services offered by private providers that would likely emerge around risk scores – offering services to provide more detailed interpretation of their results.

The concern is that it'll just worsen existing social inequalities, and it will add more into the mix. I feel like because it'll be branded as new, something unique, it'll be used as a bit of a cover for the fact that these social inequalities are getting worse. 'Oh, but we're in a new period, but we've got to get better. Look at this new term'. It just delays anything actually changing for the better, because they're trying to get away with it.

Participant, Newcastle

I'm wondering, knowing about the test results, is it going to affect people who come from more different backgrounds more than people who are perhaps well-educated, or they have more money in their pocket? I guess if you go to a food bank, you don't have much of a choice in terms of making those healthy choices if you don't have money to make fruit and vegetables and other more healthy stuff. We're not all equal in how we can [take] action.

Participant, London

Burden on the NHS

Overburdening the NHS with demands for genomic risk information and for follow-up support are the most prevalent concerns expressed by participants. Several talked about their perception that currently most adults in the UK do not have regular contact with the NHS. They wondered whether sharing risk information with all adults could lead to many more people having regular contact and potentially overwhelming the service.

I just feel like doctors and pharmacists, whoever it is, have got enough to do. And I feel like this is putting a lot more in the mix when you've not really got anything concrete at the end of it. It's not concrete because it all says potentially and it could be and so you're not actually going with it, you're taking a gamble on all of this.

Participant, London

If you give clinical feedback, then you're going to have to have a whole layer of counselling, support, and there's probably not enough support in the existing system anyway for existing diagnosis without genomics being added to it.

Participant, Newcastle

Participants questioned how demand for testing coming from the family members of those found to be at high risk would be managed. Participants are also concerned about the NHS being exposed to liability and sued because of what genomic risk information was recorded, what was shared and how it was interpreted.

Telling somebody they're low risk doesn't mean they're not going to develop a condition? Yeah. And does that leave the NHS liable at some point? Because they've told you you're green across the board, but then you have a heart attack two years later.

Participant, Newcastle

Participants are concerned about how joined up different parts of the NHS are, as well as how connected the NHS is with other organisations who would need to support the actions stemming from risk information.

It seems like it's working in silo. What are the other systems around, individuals or in the community? Do I then get to see my GP more? Do I get more health checks allocated to me. Do I get to see social prescribing. Do I get best preference to exercise centres. How does this work with the current system?

Participant, Newcastle

6.4 Implementation

This section explores participants' thoughts and expectations for how actionable risk would be implemented into the NHS.

Polygenic vs monogenic

During the workshops, participants heard specialist speakers share a range of views on the utility of sharing PRS and some monogenic findings as part of mainstream preventive healthcare. Words of caution on PRS included concerns about levels of uncertainty, false positives and false negatives. As the dialogue process drew to its conclusion, many participants felt that PRS need further research before they are used to inform health actions.

It's almost like there's two loads of data... I am happy for my data to be held by the library, but this moment in time I am not happy for that information to be on my NHS record. The way things stand at the moment, because I can't foresee the advantages at all, I wouldn't be happy for that information to be on my health record. There are too many variables that we don't know about. I think a lot of what Aroon said yesterday kind of makes me think what are the benefits of this information unless it's for the monogenic conditions that they're currently using genetic and genomics for.

Participant, Newcastle

Some participants hope that PRS could be drawn into a person's risk factors when more is known. In the meantime, many said that they were interested in receiving monogenic feedback. Monogenic is seen as more certain in its health impact and therefore more likely to need action.

I think if I was to take the test personally now, I'd want to know what my monogenic was but not the PRS because they're not quite established yet. But maybe in the background doctors, scientists or whatever are analysing that data and they decide I've got a high score, so they invite me to an early screening for prostate cancer for example. So, it changes maybe what happens in the background, but you don't need to know it yourself?

Participant, London

Responses to specific health conditions

Heart disease: preventability makes it the most straightforward for risk feedback

Cancer, cardiovascular disease (CVD) and dementia were the health conditions that the public dialogue used as case studies to discuss actionable risk. Participants' responses to the prospect of receiving risk information differed considerably based on the type of health condition.

The factors that matter to participants when considering different conditions for risk monitoring include:

- Preventability e.g. statins, lifestyle factors;
- Treatability e.g. radiotherapy, cancer drugs;
- Measurability: e.g. cholesterol level;
- Prevalence.

CVD raises few concerns for participants, and several said it felt like the most straightforward condition to provide feedback on because of its potential preventability, through statins and lifestyle, treatability and its prevalence in the population.

I feel like cholesterol and heart disease.. they were saying before they're going to choose some of the higher risk, most high profile diseases to look into first. I think most people would be in agreement that high cholesterol is one of those things that we're on board with it being included.

Participant, London

Cancer: more complex but has potential for tailored screening

Cancer, given that there are so many different types and outcomes, is seen as a more complex condition to include in risk feedback. However, given earlier diagnosis is so important to surviving cancer, participants are hopeful that a better understanding of potential risk of cancer could lead to, for example, more tailored screening.

I think it's a good... because the earlier you catch something, surely more chance you have to treat it. So, I'm back to where I was on the first day. I think it's phenomenal. You're not diagnosing someone with cancer and then put through a plan of how you remediate and try and treat that you're just saying there's a possibility you may get it at some point in your life, and because of that we're now going to monitor you somehow.

Participant, London

On the flip side, some participants are concerned that if people are told that they don't carry the BRCA gene (most inherited cases of breast cancer are associated with mutations in two genes: BRCA1 and BRCA2), then they might not take up future breast screening invitations.

Dementia: fear inducing and potentially life limiting

Responses to the potential of sharing risk information for dementia were significantly more cautious and in some cases more fearful than for CVD or cancer. Several factors lie behind participants' caution and fear. Firstly, the lack of a cure for dementia or proven effective interventions to slow its progress. Secondly, the evidence about risk in relation to dementia is less certain than for other conditions. Dementia is seen as less 'measurable' than conditions such as CVD and cancer, with biological data such as cholesterol levels as indicators for risk.

It feels like it's harder to pin down...with cancer, you can look at T-cell levels... and you can look at your cholesterol levels. So there isn't a number that you can put on how far advanced somebody's dementia is.

Participant, London

Dementia is also seen as having more widely different and hard to predict effects on a person's health, mental capacity and personality. Added to this is the perspective that dementia is a health condition that affects every aspect of a person's life and who they are as a human being.

Different forms of dementia affect people in such different ways... Terry Pratchett couldn't put his socks on, but he could still write novels. And he had early onset dementia. Versus me granddad could go wandering down the high street, not a problem, but he wouldn't have a clue where he was.

Participant, London

For many, being given an elevated risk of dementia result would mean living under a dark cloud, always watchful for symptoms. They feel that the anxiety it could cause could lead to its own set of health problems.

You want to be kind of carefree in life, to be happy, not anxious, not saying, "you look a bit different today darling", "do I?" ... It's like, crikey, is it the dementia coming? No, but God forbid.

Participant, London

Participants who said that they or their partners have a family history of dementia have different perspectives on whether or not they would choose to receive risk information. Those that did hoped for risk information to guide preparations and adaptations for life ahead. Others thought that people are already aware of a family history of dementia and questioned if genetic information would change anything.

I just spoke to my mum and my sister about this and another common thread, dementia, came up because we've got a history of dementia in our family. So my mum was keen because I think, if my Gran was diagnosed earlier we would have had more time to spend with her.

Participant, Newcastle

People that have a genetic risk of dementia, people know that...well, I do have a high risk of getting dementia so what good is that going to do, saying oh you actually do have the genetic risk when it's like it's such a small part of what goes into deciding, it's not the be-all and end-all of deciding factors and if people already know that they have a family history of it, then what does that give them?

Participant, Newcastle

If dementia risk is to be shared, participants expect to understand the importance of genetic versus lifestyle factors, to help guide their behaviours and choices.

I think there needs to be information given on dementia as a specific disease and what proportion of it is actionable and what things you can do. So, for example, your actionability score was measured, and you said for a certain disease that your lifestyle factors basically influencing the outcome is at 10% or something like that versus if it was 50% genetic type stuff, then that would influence how you thought about it.

Participant, Newcastle

Context for communicating risk information: how health test results are shared now and need for pre-assessment?

The chapter began by describing why genomic risk is a tricky proposition that drifts towards seeming like a diagnosis. The number of 'what ifs' around the scores and the actions makes it difficult for many participants to feel confident about its utility, particularly for PRS.

Just because you have a higher risk doesn't mean you're going to get it. And then just because you have a lower risk doesn't mean you're not going to get it. And then trying to communicate that is really tricky, and what that means for individual people is really tricky. Having to communicate all of that uncertainty to someone and then also why you would or wouldn't take this form of treatment. It adds a lot of complexity and sometimes a lot more information in this case, when it comes to predicting a risk...there's just a lot to it.

Participant, London

Participants talked about their current experiences of receiving health test results. Several said the information was either extremely high level or bafflingly detailed: from 'we've had your results back, nothing to worry about' to cholesterol test results that are difficult to understand because the numbers aren't contextualised and the language is

too technical. They see this as context for receiving 'risk scores' in the future. They wondered whether the way risk information is shared would learn from current practice and improve.

With a lot of GPs, after you do a blood test, they will not tell you what your number is. They will just tell you, you're fine. Or just go on the app and say, you're normal. You're borderline or you're fine.

Participant, London

I got all these figures that I couldn't make head nor tail of, to be honest with you, because there's good cholesterol, bad cholesterol, whatever, averages... I regard myself as reasonably intelligent, but it took an awful lot of Googling and sorting out before I could make head nor tail of it.

Participant, Newcastle

During several discussions, participants wondered whether in the future people should be 'assessed' for their psychological 'suitability' for receiving actionable risk information. Many spoke about their own and others different attitudes to how much health information you want. There is a sense that risk information should be a universal right but a personal choice. It is interesting to note that no one spoke in these terms about pharmacogenomics, which was seen as more tangible and universally beneficial.

We all have a different attitude to risk, and very often when you're taking out a financial product, they say we need to assess your attitude to risk to see whether you want a safe product or a kind of more of a gambling product, and it's the same with this.

Participant, London

Timing actionable risk information: early enough to take action, not so early as to limit life

When discussing the 'when' of sharing risk information, most participants talked about the time in life when taking action felt appropriate and was actionable. Telling someone when they are 25 that they have a higher than average risk of dementia, but without any concrete actions to reduce this risk is seen as unethical. Participants spoke about the middle age years as a time when people feel more conscious of their health and more likely to take on board suggestions. Integrating actionable risk into the NHS Health Check for people aged 40+ was suggested by several participants.

When you go for a test at forty years old or within the next few years after turning 40, you want to know if there's something that you need to be watching...and it's kind of done now anyway, but you can do it with a genetic test to just amplify those.

Participant, London

How actionable risk information is shared initially and over time: Low, medium, high and including other factors

Ensuring risk information is clear, relatable and engaging is seen as absolutely essential. Risk must be paired with actions. This public dialogue did not deep dive into specific risk communication examples or formats. Instead, participants discussed their own experiences and combined these with their growing understanding of the programme to suggest ways to share risk information and actions.

Visualising risk information is seen as extremely helpful. Participants shared several ideas in this vein. A good number of participants said they found the presentation using different coloured blocks (genetic factors = blue / environment/lifestyle/ chance = pink) during workshop 2 helpful for understanding the different contributing factors that add up to a higher or lower risk level. Participants also mentioned the use of

traffic lights or 'weather warning' style imagery to communicate risk levels.

You know when you look at a weather app and it says red warning, amber warning, yellow warning, it tells you what they mean. Something like that would be a lot better because that would stop the overload of staff. And then maybe if you had a red warning, that's when you need to book an appointment. But the others, just like, well, yellow warning, change your diet, these are some things you could do. Amber, you know, maybe a change of medication, stronger statin or something. At least it would give you a signpost rather than just leaving you left wondering what that means.

Participant, Newcastle

Medium risk is seen as a tricky scoring – is it closer to low or closer to high? In a similar vein, unless something is very low e.g. less than 5%, then anything above that feels like it needs attention.

Well, I would feel comfortable, if it was like 5% then I wouldn't worry about it, but obviously if it was like going to 20%, then I'd like to know more, if they could be accurate or not. Which I know it's very difficult...

Participant, London

Some participants spoke about finding numbers and risk relative to the wider population helpful to understanding and contextualising their level of risk.

I think the data should be more accurate in the next 10 years, data modelling more accurate. I think it needs to be explained in real terms...: the population has a 1% chance of risk of dementia. You have a 1.2% chance. Put it in real numbers.

Participant, London

A few participants, particularly those who work with data, would want access to the underlying data so they could interrogate it themselves.

I do a lot of work with graphs but there's a certain type of graph I see a lot of times where you have like a line of best fit and then uncertainties so like with 95% confidence, we can say that 20 years' time your risk will be between 50% and 20% I'd want all that if I was a patient I'd want to download it to digest myself.

Participant, London

Alongside how risk information is communicated sits the expectation among many participants that this information will be integrated into a person's healthcare record and used over time and be updated as more information becomes available.

In the future, participants expect to see apps and AI being used to help tailor information provision and adjust risk scores based on current lifestyle and any changes and revisit it over time, to help demonstrate impact and where further changes are needed.

This is where you could see AI being very useful because what you'd want is a matrix, really, of somebody's situation, which would include things like their job, how old they are.

Participant, London

If it's a condition that what your lifestyle also affects, I think that should be noted. Maybe you could try and quantify your relative risk in terms of environmental factors, and then combine the two. And then in the app or however, you can do two graphs. One, your expected risk and how that increases over time if you stay how you are. And then another graph showing how your risk maybe decreases if you change the environmental factors.

Participant, London

Access to risk scores: universal for HCPs

Just as for PGx, participants largely support universal access to risk scores for HCPs. There is the perception that whilst de-identified genomic data is held in a separate secure

database (the NGRL), the findings based on it: your risk scores and PGx data is already held within your NHS record.

Everyone in the ecosystem, anyone who could have contact with you. Because what's the point otherwise?

Participant, London

The act of sequencing the whole genome raised questions among participants throughout the dialogue: what PGx, diagnostic and risk information might be available, who might have sight of this information and whether it would be shared with the individual. For many, there is great discomfort with the thought that HCPs could know something about a person and that because it is not treatable, it would not be shared. Many participants are clear that they did not want risk information they could not act on, but they also questioned how incidental diagnostic findings with a strong bearing on their health would be handled, including whether they would be shared automatically or only made available on request. For example, if someone had consented to receive risk scores on heart disease, but their whole genome sequence indicates they have the gene for Huntington's Disease, would they be told?

Channels for sharing actionable risk information: apps and access to an HCP to speak to

Many participants said they would expect to receive risk and action information via the NHS App. Several spoke about how the amount of personal health data available on their NHS App has expanded recently and so transformed their perceptions of it as a channel for receiving health information.

I think the NHS App is really good actually, it gives you all the tests. You don't have to worry, you don't have to call up doctors all the time now, it just tells you, so I think it's much better.

Participant, London

There are hopes that as well as delivering risk information, the NHS App would also help with the associated actions and be updated over time to encourage and support risk mitigating behaviours.

That's where the NHS App will come in. On the app, you should be able to see maybe like a section that goes with actionable risk, maybe where the services are ...so that she can always make reference to it. And if there are any changes, like she started to take some steps and there's a change in the risk level, it should be communicated as well through the app. So, it kind of encourages... One place to do it all. Just encourages her to do it.

Participant, London

Participants spoke about the need to consider other channels beyond apps for those without digital connectivity.

The level of risk and type of health condition determines whether people want the option to speak with a healthcare professional. If the risk score is high or higher than average, many participants said they would want the option to speak to someone so that they could ask questions about the risk, check assumptions and be clear on the options for actions to take. In terms of who the professional is, many spoke about GPs 'struggling' and just being too time pressed. They felt they would have confidence in and get more time with a nurse, condition specialist, pharmacist or other professional.

A nurse or someone who's got medical knowledge and can interpret your results and explain it to you and this is what it means, this is how it works, it doesn't have to be a GP who only has 10 minutes per person. You could have half an hour or an hour per person, depending on what the risk is.

Participant, London

I feel like talking about cholesterol levels and things like that might be something that a pharmacist is trained in and also has a capacity to do. I don't think that telling someone they might have cancer or something would be the job of a pharmacist. But with the cholesterol level, yeah, definitely. I think that can also help with taking the pressure off.

Participant, London

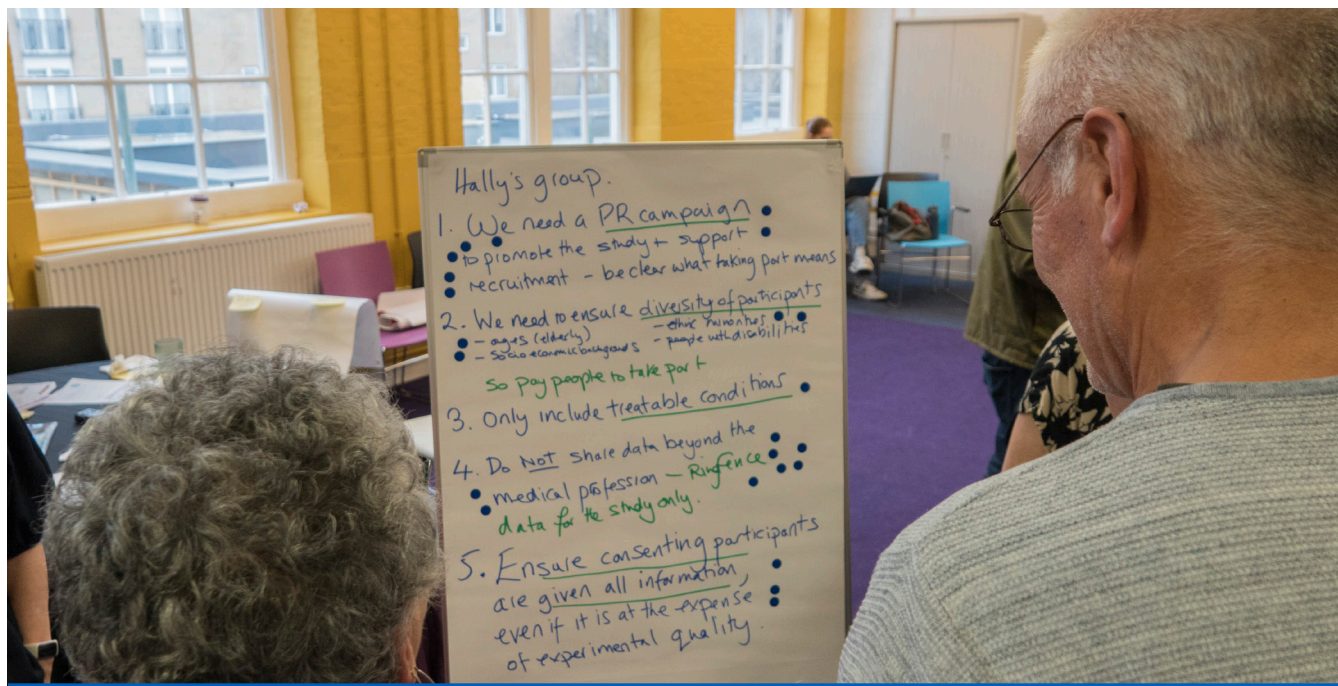
Actionability: hopes for personalisation and lifestyle changes before medication

Preventive healthcare is described as 'uncertain' and 'ephemeral' by some participants. There are concerns that people would receive a risk score, but then file it away under 'not for now' and complacency would set in. For these reasons there were many conversations about how actions informed by people's risk scores may need to be supported by more than just a link to a website or a leaflet from your GP surgery. For many, the ideal would be to meet with a healthcare professional to talk through options and come up with a plan tailored to your risk score and lifestyle, but this is acknowledged to likely be expensive.

I think especially with preventative health care, everything is so uncertain and the rewards are so ephemeral. We already know that diet and exercise is going to improve our health outcomes. But I don't do it. But if you had somebody that you could talk to, to explore your risks and how you can best navigate them, so you can wrap your head around this stuff, that would be great. Probably very expensive to do if we all had somebody. But it is ideal.

Participant, Newcastle

With expense in mind, several participants spoke about the potential for AI to give tailored advice in the future.



A London small group's top 5 recommendations.

Originally, I was thinking face-to-face is definitely the way forward. But as we said, the world could be a completely different place. So there could be an AI chat facility which feels like you're speaking... to a real human being.

Participant, London

I think by 2036 the explosion and expansion of AI will lead to AI agent specialists. Even if some are very human, they'll be very personal, and by then they won't hallucinate. But an AI agent could definitely talk to a person one-on-one and provide pathways as well. So, within 10 years, that's just going to be a new type of vehicle.

Participant, Newcastle

Many participants hope that actions to reduce risk of future health conditions could be lifestyle led and only resort to medications if absolutely necessary. Some suggested discounts at gyms triggered by presenting your risk score. Other suggestions were for links to forums where people with common risk levels could gather and share tips.

If we are told that there are lifestyle changes that we can make, that would be the first thing we would like to know. If there's something we can do ourselves then that's great but... if not what medication is there because it's not going to necessarily prevent it but it's going to delay it and give us a better quality of life.

Participant London

7. Research and data use

This chapter explores participants' views on the uses of genomic data, with a focus on research. Many support de-identified genomic data being used for medical research purposes and see benefits for the individual and society. But, because of the unique nature of genomic information, participants have significant concerns around data management and security. Participants raised questions around private companies having access to genomic databases, and the potential longevity of genomic research programmes compounds concerns about mission creep and how changes in government could affect how genomic data is used in the future. A consistent finding from throughout the dialogue is that participants feel strongly that genomic data should only be used within healthcare or health research.

7.1 Support for genomic data being used in research: future treatments and planning

Many participants express support for de-identified genomic data being used for medical research purposes and for their own data to be used in this way. They see several benefits of genomic research for society. These include expanding understanding of genetics and improving healthcare outcomes, for example preventing disease and finding cures and predicting future health and social care needs.

So, creating all this data now, storing this data now, and allowing it to be used for research purposes, there are things that aren't curable now. That will be curable. That's it. It's a good thing.

Participant, Newcastle

Participants see taking part in the research study as an opportunity for the individual to receive improved health care, while also being of benefit to wider society.

I'm happy for my data to be used to research and let there be findings that will improve healthcare, not just for me but for everybody as well.

Participant, Newcastle

Some focus on the longer-term benefits of genomic research to future generations.

The benefit isn't for myself; it's for my children and my friends' children... I've had very positive experiences about the NHS.

Participant, Newcastle

Some comment that they would be happy to contribute their genomic data for research, even though they would not want to receive personal feedback themselves.

My personal feeling is, I don't want to know. But I think I would give a sample to the Genomics England, but I don't want to know the results.

Participant, London

7.2 The nature of genomic data raises unique concerns about data use and management

While many participants support genomic data being used for research purposes as well as in mainstream healthcare, they have significant concerns around data management, safety, and security in relation to both the NGRL and the NHS, and the interactions between them.

Participants described the nature of genomic data as an “essential piece of yourself”, “it’s your soul basically”; that is unchangeable and can be stored for the long term as opposed to say a blood test or data on a temporary health condition. Participants feel that it is intensely personal and holds more than current medical data; it is about who they are as a person, their ancestry, as well as holding information that may concern their relatives and generations to come. This indicates for many a special degree of care is needed when handling and storing it.

But having a full sequence of what makes me ‘me’ is a very powerful set of data to be held in perpetuity by someone I’ve never met”.

Participant, London

I spoke to a few, three people...they would support the idea of genetic testing, but they said their concerns were privacy concerns. Issues like... where would the data be stored? Who would have access to it? What happens if a third party, for example, got access to it, and it gets hacked or sold to an unknown entity?

Participant, London

7.3 Where and how will the data be stored? Cost & environmental impact?

Participants are keen to understand where the research study data would be stored:

- Will the data be stored in a centralised location?
- Will it be held on one large server or across many servers?
- Whose server and data centre will the data be held in, will they belong to the NHS, Genomics England, or a private server provider?
- Will the data be stored on hard drives or in the cloud?

For some, expanding genomics into mainstream healthcare heightened concerns about access and leaks, by virtue of a greater number of organisations being involved in delivery.

Several participants raised questions and concerns around cloud-based hosting outside of the UK and the involvement of primarily US based technology companies. This focused on a sense that outsourcing data storage outside of the UK brings another layer of potential security breaches and access issues.

Potentially less stringent rules governing data or that companies holding the data might be sold and future policies both at company and government level could change to the detriment of data safety.

Can their government access it if they decide to? Can (a tech entrepreneur) access it?

Participant, London

Some participants raised concerns about the financial costs associated with collecting and storing data, and a few participants raised the associated environmental costs of data storage – both of facilities and water usage in particular.

7.4 Data protection questions in light of recent cyber attacks

Participants are keen to understand how genomic data would be protected. Some expressed concerns about the track record of the NHS in keeping data safe, as well as frequently citing examples from recent large-scale cyber-attacks in retail and banking.

What happens if the entire country's genetic data is stolen or hacked or modified even?

Participant, Newcastle

7.5 How long will data be stored in the NGRL?

Some participants are keen to understand how long genomic data would be stored in the library, given it is being used for research purposes. They want to know if it would be stored permanently or if there is a finite period it will be held for.

Some want to understand what would happen to an individual's (de-identified) genomic data when they die – if it would automatically remain part of the library data for the benefit of future research or if the next of kin could have it withdrawn. Some see the benefits for long term research for the data to be retained.

Does it stay once you've died? In order for it to be a longitudinal study, and for it to inform future generations, that would have to go on after you've passed. Can [next of kin] actually consent to it being withdrawn on your behalf even after you've died?

Participant, London

Participant A:

But I think the benefit of having it forever, because they can always, as they get better, they can always re-sequence it. Yeah. So that's the benefit of having it forever. So, if it's for a limited time, you may miss out the benefits, because as soon as you match it. For the future?

Participant B:

Yeah, because more capability will come up in the future. So rather than redo the test again, they already have the sample. It's just a case of re-sequencing it.

Participants, London

A few people are concerned about how long the physical sample (e.g., blood) that had been used to sequence a person's genome would be kept.

7.6 Importance of de-identification of data in the NGRL with issues about re-identification

Participants see value in de-identification of data in the NGRL but raised questions and had concerns about it too.

Some participants are keen to understand what would happen if researchers made a scientific breakthrough that could help people whose data is on the NGRL. They worry that people would miss out if their data was not re-identified.

Ethically, this is a de-identified library of whatever. If in a couple of years' time there was new testing that came out and it turned out that one of these samples was horrifically at risk of something (...) would there be a method of which to pull that up? Or is it just like, oh, that's it now?

Participant, Newcastle



Expert speakers present to participants at a Newcastle workshop.

De-identified data being re-identified if needed raised alarm bells, as some participants feel this means it is not fully anonymised. They argue that this is a vulnerability and describe the proposed approach to de-identification as an “illusion of privacy”.

I think we're discovering that there's this whole thing that this research project isn't actually de-identified data. It will be linked to your medical records. It is never truly going to be 100% de-identifiable, because Genomics England also need to have a way to re-identify that data back to you. And that's the concern.

Participant, Newcastle

One participant wanted to understand how the algorithm that creates the randomised research study participant ID would be robust.

I know it's a bit techy, but it's like what is the algorithm to create that randomised number? Because if a hacker could come in and figure out that algorithm, they could trace it back to you.

Participant, London

7.7 Accountability and transparency regarding genomic research

Some participants reflected on the importance of accountability and transparency in genomics research. One person was pleased that things have improved and are less likely to be covered up compared to what has happened in the past.

They acknowledge that, oh, this was going wrong, but they're trying to improve now. It's nice to see that they're not just trying to cover it up. When someone asks, they do acknowledge, OK, yeah, this happened, I don't know, 10 years ago, and it wasn't right, but now it is still improving.

Participant, London

Another participant was pleased to hear that research findings are publicly available.

And it's nice to see that we can also access stuff online as well. I didn't have any idea that I could just see stuff, like the research and stuff like that... I can go home and I can tell other people, 'if you're interested, you can just look at it online'. It's not like something that only needs to stay in this room.

Participant, London

7.8 The value of genomic data compounds concerns about access by private companies

Participants want to know who would have access to the de-identified data in the NGRL. They raised questions about pharmaceutical and private companies having access to the genomic data. Some wanted to know whether companies would have to pay to access the NGRL. Others asked whether it would be ethical for companies to make profits, and whether a condition of accessing the data would be making the results available to all.

So, do they have the duty to share their results? Or let's say they do the research and find something, and they're like, oh, I'm just going to privatise this and make profit on this rather than sharing with the NHS.

Participant, Newcastle

Many participants are concerned that valuable genomic data held would at some point be monetised or sold off by the NHS or the government. For example, they see there might be a need to get a return on the investment in the programme or to keep the data maintained in the future.

Ultimately somebody will look at this and think, we've got all this data, it's worth an absolute fortune.

Participant, London

For some, a future government with different policies on data held or NHS privatisation increases the risk of this happening. The longevity of the research study and what might happen with changing administrations over time is a concern.

Many participants worry about the possibility of employers, mortgage lenders or insurance companies gaining access to people's genomic data. There is concern that people may be required to share their genomic information, for example their risk of getting a condition, which could impact on their ability to get insurance (e.g., travel and life insurance) and the cost of it.

This is the big one for me... how long before insurance companies get a hold of it and start loading you because you get your genomic profile and they say, oh, you're 50% more at risk than xxx, so your premium's 50% more. And it worries me. I've gone through a difficult time with health in the last few years.

Participant, Newcastle

Having to declare genomic information feels like a real possibility for some, because of the need to declare their medical history when currently getting travel or life insurance.

A few speculated that if a mortgage company had access to a person's genomic data, it might affect their ability to get a mortgage.



London participants during a carousel activity.

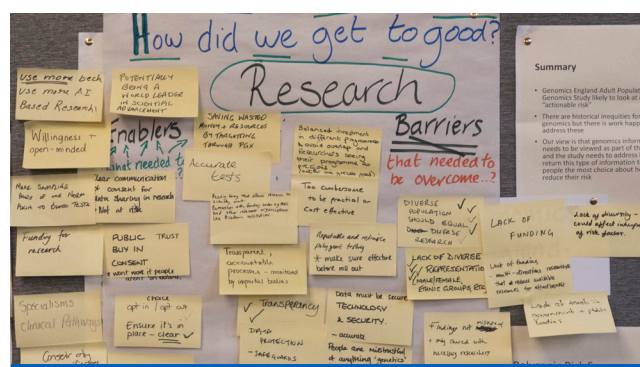
7.9 Mission creep: collecting genomic data in an uncertain political climate

There is widespread concern about mission creep and the potential for state-owned genomic databases, such as the NGRL, and the plethora of insights they provide, to be used by government for other reasons such as criminal justice, digital IDs or immigration control. Many highlighted the uncertainty they felt over what future governments might do. They worry that even though the intention is for genomic data to be used solely for health research, this could change under a different government in years to come.

One of the issues is with the governments changing every four years, policies come in... Ultimately, they [the government] can go to the courts, and the courts can decide that you have to release the data. So, the consent, regardless to what we put, the people we put in power can just overpower us anyway.

Participant, Newcastle

Some participants are concerned that without proper controls, law enforcement could eventually push for access to the genomic database, starting with serious crimes but gradually expanding its use over time.



Participant discussion of the barriers and enablers to good research.

So, you're putting this information into a central database, and then we'd know that the plan is to use it for medical care. Then you've got somebody who goes out and chops up four people, and there's no evidence on them, but they've left DNA evidence. Okay. At that point, there's going to be a strong argument from law enforcement to be able to access this. And then what could be the implications from there? Where do you then put the line in, if you're saying, okay, they can go in and access the database to get evidence for murders. Okay, well, we're going to lower the threshold slightly... And where does it stop?

Participant, Newcastle

For some, there is simply a sense of unease that people may find out things about them they did not want to be public.

A few participants expressed concerns that genetic data could be stolen or hacked and used against the UK. This included by hostile regimes, or being used to create targeted biological weapons or for as yet unknown uses.

I guess we don't know what anyone or any hostile country can do with a nation's genomic data, for example. And not knowing that risk, in my opinion, is quite important. So, the safety of the data, to me, is important, because of the unknown, the future unknowns.

Participant, London

Several participants suggested that if genomic data began to be used for nefarious reasons, there should be a close-down strategy with a way for databases to be destroyed.

8. Barriers to the success of the research study and future roll out of genomics for preventive healthcare

This chapter explores the factors that could hinder the success of the research study and any future roll out. Participants think that the cost of the research study and potential roll out could lead to calls for it to be halted to divert funds to meet immediate NHS needs.

The current disjointed state of the NHS is seen as a hindrance to effective implementation of preventive healthcare measures. The lack of diversity in genomic data and its implications for finding reliability is another potential threat to the research study's credibility. The evidence base around genomic risk in the context of other health factors is a question mark for many participants.

I just think the most massive opportunity cost of this is putting so much money into genomics testing when, as a basis, healthcare is underfunded. You can then say, hey, you have a high risk of having this disease and we still don't have a cure for it. Why isn't the money put over there instead?

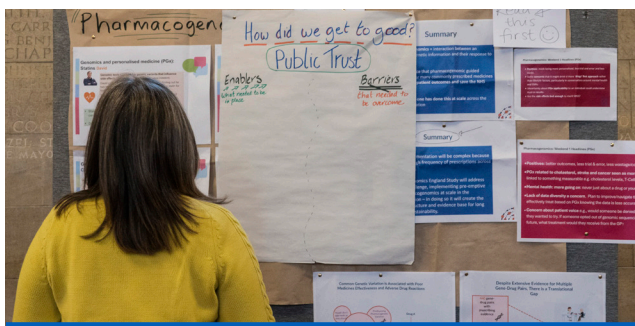
Participant, London

8.1 Concerns about cost implications

In conversations about the cost of the research study and roll out of genomics to the national budget, and to the NHS, many participants expressed concerns about how funding is prioritised. Some expressed preferences for funding to be used elsewhere, identifying existing preventive healthcare interventions, digital NHS systems, and existing NHS treatment work as underfunded areas in need of greater, or renewed, support.

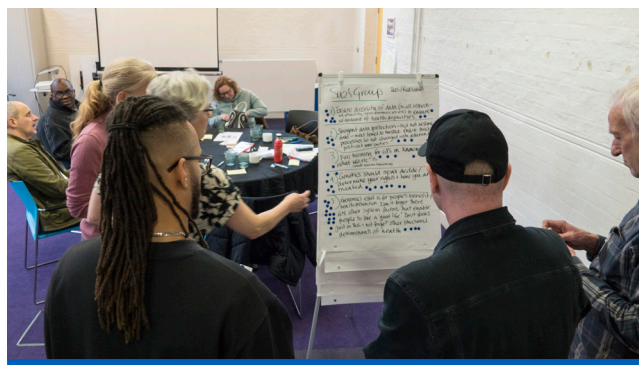
Some participants are concerned that genomic testing might be made available to the public at a cost for individuals, rather than as part of a healthcare offering that is free at the point of use. There are a few implications of this concern; chiefly, that the NHS would operate under a two-tier system with less effective healthcare for those on lower incomes, without the funds for genomic testing. Participants also highlighted cost to individuals as a barrier for the efficacy of developing genomics research, arguing that if genomics testing isn't available for free, people won't engage with it, and research would be less effective.

Some participants questioned whether financial investment in genomic research and roll out pays off for the public. They assume that the limited current applications of genomic testing mean that significant



Participant at a Newcastle workshop.

benefits would only apply to future generations, but that the cost would be shouldered by the public now. There is also persistent concern that if the cost of genomic testing and roll out is supported by private funders, their motivations might not be in the public interest.



Participants at a London workshop.

8.2 Strain on NHS resource

Participants brought up long waiting lists, struggles to get appointments with HCPs, and patients being treated in corridors due to overrun hospital departments. Some are worried that genomic testing for preventive healthcare would place additional strain on a service that some perceived to already be failing patients, worsening the situation.

Could it just cause a lot more work in a system that's already buckling under pressure?

Participant, Newcastle

Some participants think that NHS staff are already overworked and do not have the time needed to learn about and manage the roll out of genomic testing. Several identify GPs and others working in primary care as those most likely to shoulder this workload.

Participants talked about wanting to see the NHS get the basics right and build a foundation stable enough to take on the workload associated with genomic testing. Some reflected that existing pressures are likely to continue to mount as the population ages, with others identifying the lasting impact of Covid as a key issue.

8.3 Challenges with infrastructure and logistics

Participants identified several barriers relating to infrastructure and logistics. These included the complexity of managing a roll out of genomics testing if some of the public does not want to take part in the tests or if they take part but do not want to receive their results.

Reflections on the current operations of the NHS continued as part of these conversations; many participants said that the NHS is not joined up across the regions of the UK, or across primary, secondary care, community and social care and other services. This is seen as a significant barrier to the introduction of genomic testing to NHS systems, particularly its digital systems. Participants reflected on the existing 'post code lottery' they perceive in NHS treatment and waiting times across the UK, expecting that rolling out genomics could contribute further to this imbalance.

Concerns were also raised about rolling out genomics testing before the necessary support systems were in place to help people manage and understand their results. Participants anticipate that people receiving certain findings may need access to genetic counselling, help to interpret their results, and clear and supportive systems to access further information.

8.4 Lack of data diversity

The lack of data diversity in existing databases is a major concern for many participants. They question how accurate genomic-based health interventions could be for the population as a whole given these gaps in the data that they rely on. Several participants expressed surprise at the extent of data gaps, and the data imbalance across research projects and health data banks, with minoritised ethnic communities consistently underrepresented.

Participants identified two key interconnected problems with the lack of data diversity; firstly, that if data for a range of ethnicities isn't represented, then healthcare outcomes for people of those ethnicities will be less effective. Secondly, recognition of these poorer outcomes will lead to less trust and engagement in genomics testing from people with underrepresented ethnicities. They worry that the issue of insufficiently diverse data will self-perpetuate and the imbalance will deepen. Some participants questioned whether genomic feedback should be rolled out to everyone if data diversity and understanding is lacking.

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

Participant, London

During discussions about the impact of data diversity on uptake of genomic testing, participants also raised class and education as potential barriers. They expressed an expectation that those without the time and resource to seek out information on genomics would not be as likely to get involved.



Small group discussions at a London workshop.



An expert speaker engages with a small group at a London workshop.

8.5 Uncertainty around research outcomes

The uncertain outcomes of genomic testing were also raised as a barrier to its roll out in the broader population. Some participants want to see more research undertaken to find more conditions genomic testing can direct to proven, actionable treatment or measures before it is rolled out widely.

They raised a concern that a large-scale investment of time, money and other resources might be misplaced if the eventual outcomes don't result in significant improvements in public health.

This isn't something that's going to be a change in a month or a week. It should take years and years and years of work and statistical tests and analysis. And that work should still be done in my opinion. But I think it should be ticking away slowly rather than something that should be largely funded right now and immediately resourced compared to imminent changes that we could do whilst allowing the researchers to do their work.

Participant, Newcastle

9. Enablers for the research study and future roll out of genomics for preventive healthcare

This chapter sets out the enablers participants identified for the research study and any future roll out.

Public awareness, education and engagement are crucial, with participants wanting clear, tailored, multi-channel communication (including through schools, NHS channels, social media and community leaders) to build understanding and trust, alongside honesty about what the research study is and how it differs from current NHS care. Transparency is treated as a condition of trust, covering risks, outcomes, private sector involvement and uncertainty.

Strong governance and regulation are seen as essential to prevent data misuse, with suggestions including a constitution or legal framework. Participants also point to data diversity as vital. Participants expect a system of support for when findings are shared. They want to know that this will be in place so that people can understand risk versus diagnosis and access counselling if needed. Throughout, participants emphasise getting these foundations right early to build and sustain public trust.

9.1 Public awareness to help deepen understanding of genomics

A key enabler commonly identified by participants for the research study and for the roll out of genomics for preventive healthcare is public awareness, education and engagement. Participants widely

believe that improved public awareness and education will help build trust in genomics. Some said that significant funds should be committed to a coordinated involvement, education and awareness programme. Some also said it could empower the population and avoid a split between those with the resources to learn about genomics independently, and those without, who would be less likely to undertake genomic testing.

Communicating the research study: contextual considerations: big shifts vs another tool, transparency and choice

Participants place a lot of importance on a successful research study needing to communicate what it is about and how it differs from current NHS services.

Contrasting perspectives were heard on how the research study should be framed. Some think it is helpful to talk about the use of genomics in mainstream healthcare as 'just another tool', a means towards preventing ill health.

If it's not put forward as a huge revolutionary thing and explained a bit more like, a normal part of healthcare, then it would be a bit more likely to be accepted.

Participant, London

But for others, there is a need to signal a shift in emphasis in how the NHS operates and its relationship with society. In this respect, participants highlight two 'big shifts'.

**Avoiding the NHS
to prevent burden**



**engaging with the NHS
to prevent future risks.**

**An NHS focused
on diagnosis**



**an NHS also sharing
risk factors**

They believe that it is important to prepare the ground through communications and other means to help people to understand the role of the research study and potential changes to how the NHS operates.

No one really knows what the risk of anything is apart from cystic fibrosis and these really highly genetic conditions of life now. So, having genomic data out there and risk scores is such a massive departure from diagnosis... It's fundamentally really, really different. Especially at the start, because it's such a big thing, it needs big mechanisms to make sure that people are able to consent and understand, and processes by which people can have outreach support, especially at the start as well. I mean, if you go 20 years down the line and people have more of an understanding of genomics, and here you can maybe start to peel back a few of the layers and things like that. Especially at the start, I think it needs to be really thorough, as thorough as possible, in terms of risk and whatever it was.

Participant, Newcastle

So that would be quite a cultural shift. Because I think especially, you don't want to waste the NHS time by going if there's nothing actually wrong with you. So the preventative idea, I think culturally that needs to be communicated. That you're not wasting, you will be listened to. That it's useful for you to do that. I think at the minute... basically you only go if you really, really need it... But I think the idea of going preventively, rather than when you're already ill, would be a lot for people to get their heads around. It's not something we're used to.

Participant, Newcastle

It is important to many participants that clear information is shared with the public about what could and would happen to their data, what genomics data is and what its implications are. Many told us educational programmes on genomics should start in schools and target younger people. Some made comparisons between genomics and online safety education as important preparation for the modern world. They explained that young people have a higher rate of technological literacy, and that this suggests they might be more open to genomics, and might pass on and explain information to their families.

Participants considered that it might be challenging to achieve a high level of public awareness of genomics for a national roll out. Suggestions were made to address this including calling people up to attend learning workshops as with jury duty.

Participants emphasised that public awareness should focus on the benefits genomics testing could offer to the public, and that the goal should be a higher level of health literacy overall. To support this, participants said there needs to be clear recourse to reliable information sources such as the NHS website, with all accessibility standards met. In the absence of sufficient information, participants reflected, misinformation would grow.

I hope that the general population feel more empowered and educated around things like this that are impacting our health so we can make better informed decision-making.

Participant, London

Channels of communication and engagement: soaps, social media, influencers and NHS channels

Many participants think there will need to be a multi-channel approach to communication and engagement about the research study and any future wider roll-out of genomics and healthcare. They feel that this will support the building of trust in genetic data from people across the population being held by Genomics England in the NGRL.

NHS related channels such as the NHS App, TV screens in GP surgeries and whilst waiting for a call to be answered on the 111 service were suggested. However, NHS channels shouldn't be the only source of information. Some participants said they or their loved ones may not have had any contact with the NHS for several years.

In terms of reaching people and communities of all backgrounds and experiences, participants said that education and awareness materials should be tailored to different cultures, with language barriers and accessibility considered. They specified that, for example, the needs of those who aren't confident using technology or neurodiverse people should be factored in. Participants want Genomics England to go to the people they want to speak to, and not expect people to come to them to share their views. Participants stressed that people from minoritised ethnic communities should have roles in the delivery of public awareness programmes, for example through community leaders and networks. They emphasised that communications should be tailored to the needs of England's diverse population and that the importance of recognising that communication is never one-size-fits-all is essential.

Involving community leaders at a very early stage. Harking back to one of the presentations where the gentleman suggested that if a community leader said no to DNA testing, the whole community didn't take part. So, involving people who matter at a very early stage as well, so that there's no risk of suspicion or conspiracy theories behind why testing's being carried out.

Participant, London

Some of the participants in their 20s and 30s spoke about social media channels and influencers as potential channels for reaching them, but also warned that the 'pop up, swipe away' nature of social media meant that messages could be easily ignored.

I do think influencers type people doing a little video to their followers. That's what I'm saying, like influencers definitely.

Participant, London

They need a bit more reach on social media because I don't watch TV, I don't listen to radios, I don't watch Netflix and Prime, so I don't get any of this information other than like some headlines that pop up on social media but like you said yesterday if you're not interested, you're not going to click on it to see it or read it.

Participant, Newcastle

9.2 Transparency to build trust

Linked to communication and awareness, participants told us that people need to understand what the research study is doing, what the risks are, what the possible outcomes are, and whether there is private sector involvement.

This transparency is framed as a necessity in exchange for certainty and trust; participants reiterated that misinformation would have an opportunity to spread in the absence of transparent and trusted information. Participants would be entrusting the research study with their unique, unchanging genomic data and expect the right to know who is holding it and keeping it secure, who has access and what it will be used for.

Transparency is a principle that participants want Genomics England to demonstrate in its approach to communication. This includes which organisations are associated with the research study, how health conditions are chosen for sharing risk feedback and generally where there is uncertainty. They see this as important in managing public expectations.

Transparency about any sort of stakeholders in the research company or anything like that, and also honesty about what's possible and isn't possible. So, honesty about any uncertainty. If there are things they don't know, or that might be a possibility in the future, being transparent. Basically, it ties in with the last thing on there, which is managing

expectations. Just real clarity about how it's going to be used, what is looked at, what isn't looked at, and how you will find out.

Participant, Newcastle

Practical ways of demonstrating transparency include:

- Reporting on the progress of the research study at regular intervals;
- Including lessons learned from failures as well as successes;
- Not 'overselling' the benefits of PGx or actionable risk.

I was going to say, not just the good stories, they could also talk about bad stories and what they meant...In communication, in history, they always talk about where there were mistakes, and it's like, we learn from the mistakes, we don't hide the mistakes. I feel like people would trust.

Participant, Newcastle

The prescription process might be more personalised, but we're still waiting on drugs to be in the pipeline. I feel like we shouldn't oversell that aspect to people.

Participant, London

Genomic data is perceived as unique to the individual, so in many respects genomics in healthcare feels big and deterministic. For some participants, the nature of genomics may mean a person would feel compelled to use it in their healthcare, rather than a free choice. i.e. that a person should have their genome sequenced for health purposes and there could be penalties – real or imagined – if they do not. It will be important to be clear, particularly in the first few years of its introduction, that its use is a choice and not using it will not come with penalties.

If you don't want it, it's fine as well. You don't have to have it. You're not going to be penalised for that. It's entirely your choice. Yes, it's never going to be mandated.

Participant, London

Some participants looked ahead to a future scenario, following a research study, where the integration of genomics into preventive healthcare is the norm because everyone will know someone with experience of it.

Don't you think this is just a moment in time, really? Because...it's probably only a three [or] four-year period or something where people go through it. And a lot of people are signed up in that period, and then everybody goes, like, she did it, and she did it, and you spoke to your friends, and there's no problem with it. And you'll hear about the benefits anyway... It's only the early adopters that won't quite know what's going on with it. So as long as it's a good experience, then once the good outcomes have been shared within society, people will be going, oh, you want to do that?

Participant, London

9.3 Governance and regulation to prevent a slide into misuse

The governance and regulation of genomics in wider use for preventive healthcare across the country and world was an important discussion topic over the course of the dialogue. Participants stressed the importance of getting governance right at this early stage to build trust as genomic testing and feedback is rolled out and genomic research expands.

We need to pre-emptively clamp down on potential misuse and we have an opportunity potentially at the moment to be really clear on what those areas might be before you can have all the external influence.

Participant, Newcastle

A commitment to the long-term future of genomics in preventive healthcare is important to many participants. They told us plans should be put in place to ensure that changes in funding structures or governments should not hamper progress or allow drastic changes to the acceptable scope of genomic data use. One suggestion to ensure the futureproofing of governance is to create some form of constitution or legal framework to establish and protect the foundational principles by which genomics is governed. Others told us that international, protective frameworks for the use of genomics, such as the Geneva Convention, would support public trust for the long-term future of genomics research, testing and feedback, and for its use abroad.

Participants told us that to enable trust in genomics, governance and regulation structures should specify who is allowed to access or sample genomic information, on a basis of consent, in line with current legal principles around data such as GDPR. It is important to participants that private providers would be subject to the same regulations as the NHS. The expectation participants expressed is that governance should be designed to ensure genomics information is used for good. To this end, expectations of good governance also include rigorous and transparent reviews of research protocols.



Participants at an East London workshop.

9.4 Taking time to build trust through thoughtful involvement and increased data diversity

Just as they identified a lack of data diversity as a key barrier to the research study and roll out of genomics, participants considered establishing and protecting data diversity to be an important enabler. Many participants told us that they expect that demographic differences being well understood would improve the quality of research, leading to better treatment for serious conditions, and to improved health outcomes for people from minoritised ethnicities.

In addition, they perceive social benefits to data diversity in genomics, such as breaking down barriers for minoritised communities, supporting health awareness in diverse communities, and improving access to treatment and care. Some participants also suggested that improved data diversity could support those with less information about their family histories.

Participants recognise that the efforts needed to improve data diversity will be substantial. They suggest social engagement programmes and workshops to ensure people understand what Genomics England is trying to achieve, and to help Genomics England understand what is needed to make people feel safer getting involved.

Unless you know why, it's hard to counterbalance it or counteract it. But if you're speaking directly to those communities, going, what do you need from us to make this feel safer for you? Isn't that... I think that's the best that can be done, right?

Participant, Newcastle

The expectations participants have around data diversity include that the complexity of ethnic groups should be recognised and reflected in data and its use in research. They also told us it is important that samples

are made accessible to all religions and cultures; for example, alternatives to blood tests should be possible for those whose faith prohibits the drawing of blood.

9.5 A system of support when findings are shared

A crucial enabler for the roll out of genomics in preventive healthcare and for its use in studies is the creation of a system of support for when findings are shared. Participants stressed that the impact of genomics information on individuals' wellbeing could be severe. They told us people will need help understanding the feedback, including the difference between a risk and a diagnosis. They said that genomics information should be accessible to the layperson. They said that people would sometimes need plenty of time to navigate what their results mean, and access to professionals who could explain information personally, including clarifying ongoing options to manage risk.

Participants suggested experts should work with charities so that they could offer up-to-date support to mitigate anxiety and other mental health concerns. Some said that more healthcare practitioners would be needed to support increased demand. With the right support, some said information could feel empowering, rather than frightening. Many participants feel that support groups or counselling should be available, and that this support offer should be targeted to people's needs, and must not exclude anyone.

9.6 Training and support for healthcare practitioners

Additional training for healthcare practitioners is an important enabler to many of the participants. They shared an expectation that healthcare practitioners would have a certain level of knowledge about up-to-date genomics research, and reflected that significant staff time and resource would need to be ring-fenced for training.

Everyone at the GP, let's say GP and hospital, doctors and stuff like that, they all need to have the same access of information. At the same time, I think they also need to have the same understanding about genomics.

Participant, Newcastle

In addition, participants want healthcare practitioners to receive training in 'bedside manner' relating specifically to genomics. They spoke about the importance of a model for communicating information with clarity and sensitivity. They suggest that genetic counsellors should be widely employed in GP surgeries to support patients as they navigate new genomics information.

9.7 IT and system resources

Participants spoke about the importance of improving IT and system resources to support the roll out of genomics broadly across the country. Many participants feel that the NHS App could be a user-friendly platform to manage consent and view results.

Trust in the storage of data and the robustness of IT systems were flagged as important enablers of a genomics roll out. Many participants discussed the need for NHS systems to be properly integrated geographically and across systems.

I spoke to a fellow student who works with healthcare data, and it was that thing about how different healthcare systems or data storage systems, they're very isolated from each other. So one thing's useful, but by itself it's quite isolated, and it's just almost a waste of money. So it's like, is this going to be just another thing? How will they make sure that the systems actually speak to each other, so you can... get the most insights from it?

Participant, Newcastle

9.8 International collaboration and data sharing

The interaction of genomic health research in this country with international communities is of interest to many participants. While some expressed concern about how other countries might use or misuse genomic data, many discussed the benefits of sharing data and research findings to diversify the dataset, strengthen scientific and clinical evidence and avoid the duplication of important research work.

Sharing data across the international community is a helpful enabler of a successful genomics roll out for some participants, who feel that shared data would result in better quality health and research outcomes for everyone.

We talked about combining the knowledge from different countries to get the infrastructure working quicker, because if someone had a really good idea in that country and someone had a really good idea in that country, if we brought them all together, maybe we'd have the whole package.

Participant, London

This hope was tempered with caution by some participants who highlighted that the public would need to trust that other countries would uphold our expectations about how data should be used. Participants questioned who should own, or hold responsibility for, any international pool of genomic data; an existing body such as the World Health Organisation, or a less structured collaborative international network.

10. Research study design specific considerations

This chapter builds on the findings on enablers and explores points made about research study design, namely: consent; incentives; genomic sample collection and research study participant considerations (for example, whether there should be age or family history priorities) and, finally, questions about the research study.

10.1 Consent: balancing simplicity with choice

What can I consent for: research only, personalised feedback or both? PGx before actionable risk?

As the dialogue drew towards its conclusion, participants discussed their hopes and concerns for how the consent process would work, including the level of choice they would have about how their genomic data is used. Most participants assume that because the two aspects of the research study, research and personalised feedback, had been discussed at length, consent would offer the choice for either or both.

The option to only agree to your genomic data being de-identified and used in research is important to several participants. Their reasons for 'research only' are in some cases personal: they are young (e.g. in their 20s or 30s) and feel healthy, but are willing to share data that's anonymised and used for research that delivers public benefit.

I think there should be a choice of, can I give you my data and just leave? Can I just go, I signed up for your study, 32 year old male, blue eyes, 6 foot 2, here's my genetic data now, never speak to me again, and completely anonymise that.

Participant, Newcastle

In other cases, the reasons for 'research only' are related to system and service concerns about data loss or breaches. The only genomic data they want on file has to be de-identified. Some expressed a lack of confidence in the utility and validity of the information returned, particularly risk feedback, and worries about NHS staff not being trained to share information and provide follow up support.

I'm not sure how I feel about the NHS, its ability to...not look after that information properly... how they deliver that information when it is appropriate to deliver that information. Do I trust that all medical professionals will be trained to a level that they will be able to appropriately and timely divulge that information to me? No, I actually don't... that concerns me, and it could really impact my life. And I just don't know if enough has been looked into the ethics around that and...the timing of that information, and how that information is delivered directly to me.

Participant, Newcastle

For a few, the preferred option they put forward is to only use genomic data for personalised feedback: the genome sequenced, results fed back and the biological sample and genomic sequence then deleted. They feel that this is the best option for peace of mind with data security.

I guess I'm more likely to opt in to the health part of it if the data was used once and then destroyed. I guess it would increase my chances of opting in, compared to knowing if they're going to keep the data.

Participant, London

Some participants see the research and personalised feedback elements as connected – that feedback results would be informed and improved by research. They think if they want to benefit from feedback, they should contribute to the research.

If I was unhealthy, I would be reaping the benefits from sequencing my genome. And then I feel a responsibility to kind of give back and have them contain my genome. Because I know I'm from a marginalised community, they really need my data to make more informed decisions on how they can approach things in the future. I don't think I should... take benefits from it without giving something back.

Participant, Newcastle

When thinking about personalised feedback, some participants said that, for now, they would only want PGx feedback. They hope that in time, actionable risk scores might become more reliable and would want to wait for that to happen.

I imagine 99% of people would be like, I want to have the best medication that's going to work for me. So, they would tick that box and then it would be used in that way and have consented.

Participant, London

Consent channels and timing: digital with human option

Consent via digital means, likely the NHS App, is the expectation for many participants. The advantage of this is the ability to access and review information in their own time. A person can choose how much they want to read,

from headlines and bullet points or something more in depth. For some, there is also the expectation that a person could speak to someone if they had any specific questions or concerns. These participants didn't expect this person to be a GP or healthcare professional, just someone with knowledge of the programme.

I think everything moving forward with this project will be a great big technology project... The consent will be on your phone, and all the information will be on your phone or your device. So you can read through it if you want to... So it will be there, it will be spelled out for you. There may be some bullet points on the top of it, and then you can decide whether you want to tick or not. And then there may be the opportunity, if you're not comfortable with that, to ask somebody. It doesn't need to be a GP... so you could have somebody that's just offering that advice on the phone to people that feel less comfortable ... they haven't digested what's on the screen quite as well, and they still have those concerns. So therefore, you give them that talking to.

Participant, London

A few participants assume that consent will be integrated or reaffirmed in person, when the sample is about to be taken and the types of actionable risk information that are available are explained.

During the face-to-face, the doctor would have said about the risks and the benefits and the side effects of going for that while asking for the consent. For me, the consent process would be after the conversation, the benefits and what our view of taking the actionable risk finding and all of that. So, the consent can be called at the same time.

Participant, London

Consent over time: whose responsibility to check and change of use

Participants held a variety of views on ongoing consent and who is responsible for ensuring it is informed and in line with a person's preferences. Some spoke about annual or five yearly check-ins, where individuals are asked if they want their data to continue to be used for their care and in the NGRL. However, others thought the numbers that might opt out would be very small and the process would be burdensome for Genomics England/the NHS.

Participant A:

Saying they would want every five years or so to be like, do you still want us to keep your DNA? So, a position to sort of opt out and go, I don't want it anymore. And they were thinking, where will it go? How can it be used? Because everything always eventually gets used, can be used in a negative way by others outside, whether it's insurance companies or private companies.

Participant B:

I think the percentage of people who decide that at a later date they want to opt out will be very small.

Participants, London

Participants A: I think there's a real danger there. You're opening up a whole new NHS department of seeking re-consent. Every time you change something you've got to ask for consent again. That's going to cost a fortune and be counterproductive.

Participant, London

These participants feel that the onus is on the individual to be aware of their preferences and act for themselves if they wish to opt out of their genomic data being used in research or for their care.

However, as has been reported in early chapters, accessing genomic data purely for commercial gain or non-health matters, such as immigration or justice, is a redline for many

participants. A change of data access and use policy of this sort would require direct and explicit notification, a request for consent to these uses and ensuring it is easy for someone to withdraw their data either from the NGRL or from health records.

Currently we're consenting to our data being used for health. But in future, if the data is used for something else, like scope creep, I would want to consent again or not consent.

Participant, Newcastle

The use of genomic data in both research and personal healthcare in the future is remarkably broad. With this in mind several participants spoke about the importance of communicating this context to research study participants and that future usage will be wide and cannot be specified in detail. Some referred back to Covid-19, saying that ten years ago, it would not have been specified as a potential future use for genomic research data. Some think this is an obvious context.

I think when you consent at the outset, you must assume over the course of the next 5, 10, 15, 20 years, things are going to change, and change dramatically, because that's what medical science does. So, it's the height of stupidity to consent and then assume that nothing's going to change.

Participant, London

Consent in roll out: the context of cookies; organ donation; NHS care; NHS App and the 10 Year Plan

The topic of consent prompted several contextual considerations for participants. Consenting to cookies when visiting websites, the move to an 'opt out' model for organ donation and the adoption of the NHS App as a near universal tool for NHS interactions without seeming to seek active consent. This makes some participants assume that the roll out of genomics into mainstream healthcare will happen in a similar vein.

So, it's a bit like the NHS. If you did a pop-up saying, accept all this information to link you to all your genomics and stuff, just click accept, you wouldn't read all the terms and conditions. 99% of people don't, you just click accept because you think it's just an annoying pop-up. That's the way they've made it. Instead of going around and accepting, it's a bit like signing up to marketing. So, you're literally going on that website and saying, if you want to use my website, you can't deny, but click more info if you want to. So, you click accept. So that's a bit like this. Digitally, we give away so much.

Participant, Newcastle

You want everybody, the NHS App already signed you in, and because you didn't say no, you'll go when nobody told you that the NHS App was signing. And it's the same like your body parts, because there wasn't enough donation to body parts, everyone got opened up... So if this happened tomorrow, you'd just open up and put you in, only about 5% of people would come back and go, actually, that was a bit sly.

Participant, Newcastle

Some participants are concerned that this 'click away' attitude to consenting is dangerous when it's connected to genetic data. A few also said they had observed consent only being paid lip service in NHS settings, with some healthcare services being delivered without meaningful consent being discussed and obtained. They hope to see checks in place to confirm awareness of what you have signed up for.

Consent, and not under pressure. People are given time to think about it, not just say yes or no in five seconds, like it happens a lot with the NHS, and very often they don't even ask for consent. I see they say oh we're going to do this, and the patient hasn't been even asked do you want to do this yes or no, I see it all the time, and that's not consent. So having time for a properly informed consent.

Participant, London

But for others, the fact that the Government's ambitions for genomics are set out in the NHS 10 Year Health Plan makes them assume and hope that the focus will be on service delivery rather than consent.

This whole issue of consent to me is, I find it a bit annoying. It's like, why consent? Because that 10 Year Plan of the NHS going forward is that they've committed to the use of AI and genomics. Surely it should be an opt out system, not an opt-in?

Participant, Newcastle

10.2 Research study participant considerations: open to all or target those with family history, by age?

During discussions on who might and might not take part in the research study, a common theme was that younger people (particularly in their 20s) would be less likely to be interested in taking part because they are, in general, healthier and have fewer health complaints. Participants thought that the 40 and 50 age group would be the focus: old enough to be thinking more about their health and young enough to still do something about it.

I feel like 40 is a really good time to start thinking about that. You're a full adult. You're not being given that information as an 18-year-old when you're like, oh, I don't know. You're starting to be more conscious of lifestyle changes that you might want to make around your age. But it's still young enough to make a difference as well.

Participant, Newcastle

We've not outlived our life.

Participant, London

Some participants shared their own life experiences as a challenge for the research study designers to consider when developing the ways and means of taking part. In this case, a single parent with four children living on a low income. How would she notice the research study, why would she give it a second thought, what would tip her into deciding to take part?

Up until recently I was a jobless single mother, because of circumstances. So, I don't want to target jobless single mothers, but I would say a single mum who's struggling to make ends meet, who's got four kids, who has got no time. She doesn't want to think about this, she hasn't got the time to think about this. So, she could potentially be someone who could benefit from it, but because of lack of care, lack of self-care, will they go for it? So, are people going to miss out, basically, because of the circumstance?

Participant, Newcastle

On the question of whether people with a family history of health conditions should be prioritised, several participants assumed this would be the case, at least initially, rather than a more 'shot in the dark' approach of the general population.

Someone of my age might be curious if something's going to happen in the future. And if that's not taking up a lot of resource rather than focusing on... people that have got a family history of something and then looking at their genetics, does this affect them later down the line?

Participant, London

10.3 Incentives for taking part

Conversations about financial incentives for taking part in the research study often came up in the context of being paid to take part in Covid testing or being offered £10 to take part in Our Future Health. Participants think that offering a small payment could mean more people living on low incomes will sign up. However, the incentive level needs to be calibrated to the effort level needed to take part. Some participants spoke about considering the £10 offer from Our Future Health, but rejecting it when they took into account the costs of travelling twenty or more miles to the test centre.

If they want more data, then as the public, we have to be a bit more open, because we're not really that trusting with the NHS or the healthcare system. But if they don't have that data as well, that means we are also then kind of leaving that one part of the population out. So if there's incentive to give this much money, take part in this, and that also brings in the class system. If it's a financial thing, then you're more likely to attract more people in, and that means more data, which is better overall for the future as well.

Participant, London

While financial incentives are seen as useful for drawing in some borderline sceptical people and some on lower incomes, the incentive of having new, tailored information about your health was also seen as real and motivating for many.

10.4 Sample: blood = robust / saliva = convenient

There were a handful of discussions about where samples should be taken and whether the sample should be blood or saliva. Some expect to visit a hospital or GP surgery to have their sample taken. They see this going hand in hand with a conversation about consent choices, including which health conditions would be included in your feedback.

But other participants discussed home testing kits (making references to COVID testing kits) and felt this would be more convenient, particularly for those with caring responsibilities, full-time jobs or mobility issues.

Some wondered if a sample could be taken when donating blood.

A blood sample is seen as more robust by most of the participants who discussed the topic – it feels like it is more reliably and undoubtedly linked to the individual (unless a person has had a blood transfusion). A saliva sample is easier to obtain (needle phobias etc) but there are doubts about it being able to give the full picture (and what if the individual has been kissing someone?)

My blood, I think, because I could give a more detailed picture, but I might be wrong, I don't know the science behind that, so, for me, I feel like my saliva would be more inferior. That's what I would think.

Participant, Newcastle

Participants at a Newcastle workshop.



10.5 Questions about the research study

These questions came up at different moments throughout the dialogue. The

questions are included here because they provide useful insight into the issues participants wanted to better understand about the research study.

Theme	Questions
Questions about research study involvement	Is the NHS personal feedback bit now, or later after research?
	Am I giving consent to my medical history and my DNA?
	Can my data be deleted even if de-identified?
	Do I need two tests? One for PGx and one for risk?
	How much blood is needed?
	How long does it take to sequence a person's DNA?
	How will you ensure the individual's data has been sequenced correctly and what happens if it hasn't been?
	Does this genomic testing cost extra (not free on the NHS)?
Questions about the research study	How does this link with Genomics England's Generation study?
	Are there targets for representation?
	Why 150,000? Is that enough?
	Is there funding guaranteed to see this through?
	Will genomic tests become as routine as blood tests for diagnosis?
	Has genomic data collection for the research study already started?
	What are the costs associated with the study, and will it be cost effective?
	How long is the study going to run for?

11. Recommendations

These recommendations are drawn from the workshop discussions, feedback on Recollective and from the participants' recommendation statements of five key points from the final session of the last workshops (shared in green text).

They represent the optimism that most participants feel for the research study, so long as these recommendations are reflected in how the research study is planned, designed and delivered.

11.1 Data that is secure and used only for public and personal health

Participants believe that a government health programme asking people for their genomic data must ensure that the data will only ever be used for public good. This means only used for health e.g. treatment or research and never for immigration, policing or other non-health profiling. This means never giving access for commercial advantage that could result in individual harm (e.g. to employers, insurers).

A legal framework or constitution that will protect, as far as possible, the data from a change of government agenda is seen as the most robust way to prevent data misuse. In summary participants called for:

- Data to be only used for public and individual health, or health research, not shared with other government departments or insurers;
- No discrimination as a result of the findings: financial, insurance companies should not have access to the data;
- A secure data system should remain in health system and never politicised, weaponised or commercialised;
- A legal framework to limit access to data and prevent misuse.

11.2 Right the wrongs of previous genetic data banks and research: diverse data is vital

The research study has to be for and about everyone. Participants are clear that the research study and any future roll out must feel relevant and welcoming to all: recruitment must ensure diversity of ethnicity, gender, age, socio-economic background and disabilities.

Participants are adamant that more must be done to address the inequity in genetic data gathering and research that has focused on white Europeans. Participants mandate Genomics England with righting this wrong and ensuring that everyone, regardless of background and situation, can have confidence in genomic findings.

Many call for the research study to recruit a 'representative' sample of the population. But some participants believe that over-recruitment may be necessary to address historic gaps and health inequities.

Participants acknowledge that gaining attention, meriting consideration and winning trust will be challenging in some communities. Harm from previous health research exploitation and neglect, the current polarised and unstable political and cultural climate, and the cost-of-living crisis all need to be considered. Participants urge Genomics England to think carefully about who may be least likely to take part in the research study – for reasons linked to ethnicity, economics or education for example – and to work in partnership with communities at a grass roots

level to build trust and design pathways to support participation.

Some participants suggest incentivising involvement financially or through, for example, tailored health plans. They acknowledge financial incentives may be controversial and would need testing for impact, but they felt its necessity should be explained to reduce resentment. In summary participants wanted to ensure:

- Diversity of data in all aspects: for example, ethnic and socio-economic, to ensure a re-balancing of health disparities;
- Diversity of data through a health equity lens and ensure over-representation where needed for equity;
- Recruitment to the study is fair and representative of diverse communities by directly engaging where people are and providing incentives.



Participants at a London workshop.

11.3 Informed consent is crucial to trust / sample collection

The intensely personal nature of genomic data merits a carefully designed consent process. The components of informed consent for the research study that participants see as essential are information on:

- How data is kept secure;
- Who will have access to the data;
- Options for research only, personal feedback only or both;
- Updates on changes to the above;
- Options and steps necessary for a simple withdrawal from the research study.

Participants want to see a consent process that balances the competing imperatives of simplicity, information and choice. Simplicity to avoid overburdening and putting off those less likely to take part, the necessary information to make a proper decision and the ability to choose different levels of involvement and information. For example, could participants only opt to donate their de-identified genomic data to the NGRL for research purposes, but not receive personal health feedback?

Many participants expect consent via digital means, such as the NHS App. They value being able to access and review information in their own time. The NHS website is seen as the gold standard in terms of Plain English usage and participants hope for the same clarity. Alternative routes to take part are essential to achieve diverse involvement, particularly for those who are not online, are without the necessary technology, or for whom English is not their native language. For some, a person-to-person component to the consent process is essential whether via a phone call or potentially when the genomic sample is being taken. For others, the whole process could be

done by reviewing information and consenting online and providing a sample via a kit in the post.

For any future roll out, assurance is needed that saying no to genomic testing will not lead to experiencing a second-class NHS service. In summary:

- Consent is essential: it needs to be clear, concise, and give choice over preferences about findings returned to them, for example, only hearing back if high risk vs always hearing back, or only hearing back, if conditions can be treated;
- A well-informed consent system should ensure that participants understand the implications of sharing genomic data and the information they may receive as a result.

11.4 Building public understanding and engagement with the research study

Throughout the dialogue, participants shared their concerns that a government database for genomic data risks being characterised as part of a shift to a more surveillance, coercive society. To counter this, participants want the research study communications to have transparency at its heart: being clear about objectives and intended outcomes, timings and who is and is not involved – including commercial organisations. Genomics England, participants think, should use its years of experience in genomic healthcare for rare conditions and cancer as evidence when communicating how data can be protected and used for public good.

Both successes and failures should be shared as the research study progresses. Just communicating the successes will undermine trust, say participants. Communication also needs to address deep concerns about the research study taking resources from an already strained NHS and increasing demand if the return of findings is mismanaged or under resourced.

As highlighted in participants' recommendation on diversity of data, participants want Genomics England to partner with community organisations to build trust and learn from the experiences of minoritised ethnic communities, those from lower-socio-economic groups and disabled people. Participants in Newcastle and the North East highlight their appetite to see a truly national (rather than London/South East centric) research study. In summary, participants call for public:

- Information campaigns that speak to all generations and communities, including in the north of England;
- Multi-channel Awareness campaigns, for example using television, social media, influencers, and communications through community leaders to normalise genomic health in society.



Small group discussions at a Newcastle workshop.

11.5 Communicating with and supporting research study participants: demystifying risk, making it meaningful and supporting actions

During the dialogue, participants shared examples of poor communication of NHS health test results. Often the results were too technical to understand, or the HCP only shared them in a vague way, by saying there is “nothing to worry about”.

Participants recognise that risk findings are different to diagnostic results. They want the research study to find ways to share findings that are accessible, meaningful and inspire agency. When receiving risk findings, participants want a person to feel like they have a better understanding of their current and future health – not baffled, confused and distressed. Risk findings should always come with actions and preferably with comparators (e.g. to the general population) to aid understanding. More focused research is needed to explore this topic.

Support during the delivery of findings depends on the level of risk. To prevent distress, anxiety or denial, the option of personal contact when sharing high risk findings and advising on next steps is important to many. In addition, guidance for whether and how to share feedback with family members is essential.

AI and the NHS App are anticipated by many, and seen as acceptable to some, as the channels of interaction for receiving data, although some predict they will always want a human to consult. Key throughout is a person’s ability to interact with the research study, ask questions and not just be a passive recipient. In summary participants said:

- People need to be informed, with clear, jargon-free, language to build trust and understanding. This includes the (optional) opportunity to have a one-to-one meeting with an HCP to make sense of the findings and clear and transparent communication throughout, with the equivalent level of clarity, factual detail and accessibility as the current NHS website and App.

11.6 Pharmacogenomics (PGx) and risk of CVD – most acceptable for feedback

The promise of fewer side effects, less time and money wasted on medicines that don’t work, saving precious NHS resources: with this in mind, PGx is strongly welcomed by participants. As long as findings do not create health disparities or supply problems or lead to a greater emphasis on drug versus more holistic interventions, there is strong endorsement for it to be part of the research study.

There is almost no appetite to receive risk findings for conditions, such as dementia, that lack treatments that are proven to prevent or significantly delay diagnosis. In contrast, CVD is seen as the most ‘acceptable’ condition to receive a risk score for, notably for the accessibility of preventive treatments: e.g. diet and exercise changes and statin medication.

Cancer, given its association with mortality and its complex, often invasive treatment options and lack of a ‘statin’ equivalent to take a preventive pill, makes it a trickier proposition to receive a risk finding for. But given its prevalence and the need to

diagnose early, there are hopes it could be meaningfully included in the research study or roll out if there is evidence for preventive actions and treatability.

The evidence base for risk findings is important. Participants are concerned that the evidence for PRS and some monogenic associations is not robust. They recommend ongoing research to improve the evidence base around risk and treatment. In summary, participants recommend:

- A focus on PGx for the time being before moving towards PRS if the evidence suggests this is feasible;
- Only including treatable conditions in the research study.

11.7 Proving return on investment

Participants see the NHS as precarious and over-stretched. They said that the use of genomics for preventive healthcare needs to demonstrate that it is a wise investment. Frankness and transparency in reporting the research study's impact on preventing ill health and medication wastage is important for trust in any future roll out. In their final recommendations participants said:

- Incorporating genomics & healthcare must save money and resource for the NHS in the long run;
- Data held for a specified amount of time and Genomics England must show impact before being able to keep it for more time.

11.8 Governance and leadership: involve a range of perspectives to help plan and deliver for the long term

Linked to recommendation 11.1 on data use protected by legislation or constitution, strong leadership and governance informed by a range of perspectives are seen as vital to the success of the research study and future roll out. Participants expect to see robust, long-term planning that works hard to anticipate and plan for future challenges – such as the risk of a future government attempting to change data access policies. Oversight needs to come from a wide range of perspectives, including members of the public to ensure scrutiny of the research study for public good. In their final recommendations participants said:

- Integrate long-term planning which builds in resilience, for example, in the case of changes to government, and scalability ensuring cost-effectiveness;
- Ensure an exit strategy if data is misused: data could be destroyed if the political climate changes the original aims of the programme;
- There should be public representation on any guiding, oversight or advisory groups;
- A project like this needs strong leadership: knowledge, presence, credibility, hearts and minds, with clear messaging on aims and possible outcomes to get buy in and trust.

11.9 HCPs trained in the use of genomic data and how findings are shared with patients

HCPs must be supported through training and other means to ensure they feel confident in and informed to use genomic data in preventive healthcare. Participants do not want to be disadvantaged because their GP or other HCPs are 'out of the loop' or don't have the skills or capacity to use genomic data in prescribing and preventing poor health. As a result, participants recommended mandatory and ongoing training of HCPs together with effective use of the NHS App and integrated healthcare services.

11.10 Data stored securely to prevent inappropriate access

Participants said that genomic data must be stored securely and preferably in the UK to prevent inappropriate access.

11.11 International collaboration

International collaboration is seen as having the potential to enrich data diversity and encourage research partnerships to speed up discoveries in healthcare. As participants in London put it in their recommendations:

- International collaboration is essential to enhance results, diversify data and save money.

11.12 Genomics: yes, but keep focusing on the other factors that affect our health

By the conclusion of the dialogue, many participants saw genomics as one tool among many to help individuals, families and society lead healthier lives. They felt that investment in genomics for preventive healthcare should not come at the expense of, or distract from, investment in broader lifestyle and environmental factors. If a person is told that they are at higher risk of heart disease, but don't have access to healthier food or a safe and welcoming space to move around more, then the risk information is of little use and the investment in its provision could have been better spent elsewhere. As participants put in their recommendations:

- Genomics effort is for people's benefits / health prevention. Don't forget there are other system factors that enable people to live a 'good life'. Don't focus just on this and forget other structural determinants of health;
- Don't lose sight of context such as environment and lifestyle.



Participants watch a video presentation during a London workshop.

11.13 Conclusion

This public dialogue suggests real public goodwill towards the use of genomics in preventive healthcare, provided the foundations are laid carefully now. This goodwill depends on data being robustly protected, through a legal framework or constitution, and used only for health.

Goodwill also depends on benefits reaching everyone rather than a few, and on the NHS being supported to deliver it well. Participants see genomics not as a 'golden ticket' for better health, but as one factor among others, including lifestyle and environmental factors, that need to be addressed to achieve a society where people live lives in better health. The opportunity to deliver and learn from a dual-faced genomic research and personal preventive healthcare study is one that participants want to see the UK grasp, and become an exemplar to the world.

Participants in discussion at a London workshop.



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

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

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

Newcastle participants and facilitators at the end of the workshop programme.



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