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Genomics, Healthcare and You

Healthcare Professional Engagement Report
Prepared by RAND Europe



EUROPE

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Preface

This report was commissioned by Genomics England as part of their Genomics, Healthcare, and You engagement programme. RAND Europe in partnership with Hopkins Van Mil, The Social Agency, People Street and The Leap, were commissioned to deliver this project. This document is prepared by the RAND Europe project team following a series of engagement activities conducted with healthcare professionals.

The purpose of this report is to provide the findings from the healthcare professional engagement, to inform Genomics England as they develop a national research study which will aim to sequence the genomes of 150,000 adults in England through the **Adult Population Genomics Research Study** (known as “**the study**”).

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Abbreviations

AI	Artificial Intelligence
CNS	Clinical Nurse Specialist
FHCNS	Family History Clinical Nurse Specialist
GP	General Practitioner
GPwER	General Practitioner with Extended Role
HCP	Health Care Professional
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PH	Public health
PN	Practice nurse
RE-REC	RAND Europe Research Ethics Committee
UK	United Kingdom

Glossary of terms

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Executive summary

Overview and background

Advances in genomics and genetic screening are rapidly reshaping healthcare, offering opportunities for more personalised prevention, diagnosis, and treatment. The importance of genomics is reflected in strategic policy commitments, such as the Fit for the Future: 10 Year Health Plan and the Life Sciences Sector Plan.

As announced in these plans, Genomics England is in the process of developing a national research study which aims to sequence the genomes of 150,000 adults in England to explore applications in adult population healthcare. This development necessitates careful consideration of its impact, not only on patients and the public, but also for healthcare professionals, who will play a critical role in implementation, and the wider health system.

In this context, RAND Europe, in a partnership programme led by Hopkins Van Mil working with The Social Agency, People Street and The Leap, was commissioned to deliver the Genomics, Healthcare, and You engagement programme. This programme aims to understand public and healthcare professional perspectives and views on using genomic testing and genetic information into healthcare settings in England for the adult population. This document provides the final report from the healthcare professional strand of the engagement programme.

Methods

To complete the healthcare professional engagement, we conducted:

- A short online survey
- A series of workshops with healthcare professionals.

The engagement 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.

The survey was designed to understand healthcare professionals' familiarity and confidence in using genetic information, as well as to recruit participants for workshops across different roles, experience levels, and locations. The survey explored professionals' use and perceptions of genetic information, expected positive outcomes (such as personalised care and improved prescribing), and potential negative outcomes (including resource pressures and inequalities), and asked for demographic details to contextualise responses.

The workshops were conducted in two phases. The first phase was role-based workshops, comprised of homogenous groups, for example all general practitioners. Discussion focused on how genetic information may impact their current and future practice, impacts on patients, and their professional roles. A supplementary online discussion board was also held for those unable to attend.

The second phase were systems workshops, with mixed roles. These were 90-minute workshops to consider requirements for successful implementation, including changes to practice, training and information needs, and considerations of data access.

Survey responses were analysed using descriptive statistics and thematic analysis of free-text responses. Workshops were recorded and transcribed and then coded with both inductive and deductive methods to identify key and emerging themes. Findings were synthesised and written up to provide key themes on healthcare professionals' views on implementing and using genetic information in practice.

Findings

Our findings show that healthcare professionals are broadly optimistic about the introduction and use of genomic information in adult population healthcare, particularly its potential to enable more personalised, proactive care with improved risk prediction and prescribing decisions. However, enthusiasm is tempered by concerns around implementation. Healthcare professional concerns included risks associated with increased complexity and uncertainty, knowledge and training gaps, and issues of equity and trust (particularly for underrepresented groups).

Some of the professionals consulted, particularly family history clinical nurse specialists, use genomics routinely, while others reported more limited exposure and knowledge. This resulted in mixed views and expectations regarding impact on individual roles and workloads. For example, those more familiar with genomics noted that their day-to-day experience was less likely to change.

Key enablers for using genomics in healthcare include comprehensive and tailored training, standardised guidance and clear clinical pathways, funding, collaboration, support, and accessible information systems. Healthcare professionals highlighted the need for up-to-date national guidelines, integration into existing systems, and practical resources (for example patient communication).

Barriers and challenges identified included workforce pressures, fragmented infrastructure, and risks related to equity and inequalities.

Discussion and conclusions

Cautious optimism among healthcare professionals about the potential benefits of using genomics in healthcare is balanced by concerns around practical readiness and changes needed across and within the system. These findings echo and extend existing research and evidence.

To ensure effective implementation, the programme should be integrated in NHS structures, embed equity in both research and implementation, build and maintain trust through clear communication, and provide practical support for healthcare professionals and patients. Implementation will be shaped by differences in existing familiarity and experience in the use of genomic data. Engaging healthcare professionals in research and in the programme design requires careful consideration of timing, flexible participation options, direct recruitment strategies, sustained opportunities for involvement and attention to differences in role.

Introducing and using genomic testing and information represents not only a scientific advance in healthcare, but a complex organisational and system change. Success will depend as much on addressing professional, infrastructural and ethical considerations as on the continued development of genomic science.

1 Introduction

1.1. Background

Advances in genomics and genetic screening are rapidly transforming the landscape of healthcare. Further understanding and use of genetic and genomic information has the potential to change clinical practice, by enabling more personalised prevention, diagnosis, and treatment strategies for patients.

Genomic initiatives are increasingly implemented into care pathways and practice in England. This includes projects led by Genomics England, including the well-established and completed 100,000 Genomes Project (Genomics England 2026a) and the Generation Study (Genomics England 2026b). There is national interest in how the broader adoption of genetic and genomic testing can support improved patient outcomes and ensure that the health system is equipped to address future challenges.

The importance of genomics in healthcare has been reflected in strategic policy commitments, such as the Fit for the Future: 10 Year Health Plan, and the Life Sciences Sector Plan (NHS and UK Government 2025; UK Government 2025). These documents set out ambitions for the healthcare system and include specific aims in relation to genomic data: a system that harnesses genomic data to deliver more precise, predictive, and preventive medicine to the population. Research programmes responding to this expand the integration of genomics into mainstream services, with the NHS Genomic Medicine Service supporting and delivering many of these ambitions alongside others. As announced in the 10 Year Health Plan, and the Life Sciences Sector Plan, Genomics England is in the process of developing a national research study which aims to sequence the genomes of 150,000 adults in England to explore applications in adult population healthcare (Genomics England 2025). This expansion necessitates careful

consideration of its impact, not only on patients and the public, but also for healthcare professionals (HCP) and the wider health system, who will play a critical role in implementation.

1.2. Overview of the literature

In this section, we provide an overview of the literature related to HCP views on the use of genetic information in healthcare for the adult population. The first section draws on a previous literature review commissioned by Genomics England conducted by Fava Health¹, while the second section incorporates further literature identified as background by the RAND Europe study team.

Genomics England commissioned Fava Health to conduct a literature review on public and healthcare professional perspectives to population-level genetic testing, prior to this engagement programme. The review was shared with the partners undertaking the engagement programme and was used for background knowledge and informing the design of our data collection tools.

The Fava Health literature review draws on a global range of academic publications, covering the existing theoretical and real-world evidence related to the views of patients as well as a range of healthcare professions toward the use of genetic information in healthcare (Fava Health 2025). The structured literature review included 121 articles, 12% of which covered the views of health professionals in some capacity.

The review highlights the substantial benefits that HCPs, as well as the public, expect from genomics but note a range of substantial barriers to its use. Amongst HCPs, key barriers related to insufficient knowledge and training, limited capacity, possible negative psychosocial impacts on patients, and perceived challenges of integrating genomics into existing workflows (Fava Health 2025).

¹ Fava Health is a genomics-focused digital health company. For more information, please see: <https://www.favahealth.com/>

In what follows, we outline key findings from the Fava Health literature review as it relates to HCPs as background for the current work, including insights from the public perspective that are relevant to patients' interactions with the healthcare system.

While there were limited papers identified in the review related to UK HCP perceptions and attitudes towards genomic information, the review showed that many HCPs see its use as acceptable (Fava Health 2025). One study highlights the strong preferences of general practitioners and pharmacists to use pharmacogenomic testing as opposed to standard models of care when prescribing medications, reflecting positive views on the utility of genetic information for understanding pharmacogenomic risk (McDermott et al. 2024). Even so, these views are not uniform – while they see it as acceptable, some HCPs see the utility of genetic information to anticipate risk as limited, reflecting a cautious approach to its utility for certain use cases, including for assessing risk of developing certain diseases (Hann et al. 2017; Rosso et al. 2020). Specifically, a large number of clinical geneticists in Hann (2017), as well as European public health professionals surveyed in Rosso (2020), flag unproven or unknown connections between genetic information and risk of developing disease as a possible barrier (Hann et al. 2017; Rosso et al. 2020). Compounding this, some HCPs highlight capacity and scope creep as additional reasons for hesitation towards the use of genomic information in practice (Hann et al. 2017; Rosso et al. 2020).

In the literature reviewed, it was unclear how perceived utility and value varied across various applications of genomic information -- Mendelian risk assessment, Polygenic risk assessment, and Pharmacogenomics (Fava Health 2025). HCP views represented in the review did distinguish between different use cases, noting the utility of genetic information generally to support risk prediction and treatment as well as specifically improving

patients' health status, including creating improvements for those with chronic disease as opposed to maintaining the status quo (Marzuillo et al. 2014). Prevention was another key area of value recognised by the cited articles, including to support decisions to include patients in screening and the frequency of screening (Marzuillo et al. 2014; Smit et al. 2019).

There was divergence in views amongst healthcare professionals surrounding the utility of general genetic testing (Fava Health 2025). Divergent views namely related to the barriers to implementing widespread genetic testing – Hann (2017) and Rosso (2020) highlight that GPs and public health professionals may have less ability to engage with genetic information due to their need for broad knowledge as part of their traditional roles, while clinical geneticists have expertise in genetic information but may have reservations about their capacity to engage with testing and negative views on effectiveness (Hann et al. 2017; Rosso et al. 2020). As such, the literature highlighted the importance of engagement with non-genetic specialist HCPs as part of rollout of genomics programmes (Rosso et al. 2020).

Key support needs highlighted by HCPs in reviewed research related to initial and ongoing training, including on the specific importance of genetic information for prevention, treatment, and future risk as well as in the best ways to communicate information to patients (Fava Health 2025). In two studies, HCPs from Italy and Australia flagged that they felt the need for more knowledge and education on the meaning and use of genetic information as well as knowledge on how to effectively communicate findings to patients (Marzuillo et al. 2014; Smit et al. 2019). In particular, of the 22 HCPs interviewed by Smit et al (2019), many saw genomics as an integral part of their future work, underlining the importance of knowledge and upskilling (Smit et al. 2019). Specifically, HCPs underlined the need for

undergraduate education, as well as upskilling or reskilling for already qualified professionals, which could include engagement with public health genomics work (Rosso et al. 2020).

HCPs had several concerns on the system-level implementation of genetic testing to inform healthcare within the literature included (Fava Health 2025). Some noted the potential negative impact of genetic testing as a possible distraction from other, well-known drivers of health at a system level, including the social and environmental determinants of patient health (Rosso et al. 2020). Others were concerned with system-wide factors related to implementation – for instance, noting the importance of service design to support timely, actionable results and infrastructure needs such as electronic health record integration (McDermott et al. 2024). This, in turn, is shaped by other factors which are seen to require system level action, including addressing possible data sharing concerns and ensuring patient literacy of genetic information (Tommel et al. 2023). The review highlights limited real-world evidence on the impacts of large population genomics programmes which was seen to underly these concerns and considerations, highlighting the need for further evidence to support service design and implementation.

The impact of genetic testing on patients, and the use of genetic data in healthcare, was seen by HCPs covered in this review as potentially highly impactful (Fava Health 2025). Within the review, HCPs across the included literature flagged possible benefits, such as prevention, life-saving treatment, and non-clinical benefits such as increased autonomy (Hann et al. 2017). However, HCPs in the review also noted risks including negative psychological impacts (such as anxiety or worry) over known impacts or variants of unknown significance, as well as negative medical consequences (such as patients ceasing medication) as a result of genetic testing (Tommel et al. 2023). As such, articles included in the review highlighted the need for support for patients to understand results and follow-up actions (Tommel et al. 2023).

Additional insights from the literature

To supplement the review by Fava Health, RAND Europe carried out a wider search of the additional academic and grey literature relevant to understanding healthcare professional's experience of, and attitudes towards, genomics. Additional literature was identified by expert review and included literature published since the Fava Health review, including a scoping review of 52 studies on building capacity for genomics in primary care published by Dunlop et al. (2025). It revealed a range of additional insights, including views converging with that from the previous review, as well as additional relevant themes and examples.

There is variation in the understanding and use of genetic information in practice amongst HCPs, as well as what HCPs see as their responsibility regarding genetic information. Knowledge of research into genetics and potential applications of genetic information, for example polygenic risk scores, is variable across HCPs involved in adult population healthcare. For example, a 2022 survey of UK GPs found that 49% were not familiar with polygenic risk scores (Ayoub et al. 2023). 41% of UK GPs surveyed between 2017 and 2018 had not heard of Genomics England's 100,000 Genomes Project (Evans et al. 2020). Moreover, of the Canadian non-genetic specialists HCPs surveyed in Lapointe et al. (2022), 61% reported that they did not have enough knowledge about the use of polygenic risk scores for breast cancer screening (Lapointe et al. 2022). In their scoping review Dunlop et al. (2025) found that knowledge was a major barrier to, and enabler of, the implementation of genomics in primary care.

There are however positive attitudes towards the use of genetic information in practice, even if some applications fall outside of HCPs' current roles. For example, some primary care providers in the United States highlight the need for education on some aspects of genetics, beyond what many of

them saw as their role in genomics – namely, making referral decisions and educating families about what genetic information means (Kenneson et al. 2025). Building on this, many primary care HCPs in the study cited an interest in other areas of genomics, including understanding the science behind genetics, and co-management of patients with genetic conditions with other HCPs (Kenneson et al. 2025). Specifically related to breast cancer, the majority of UK GPs surveyed by Ayoub et al (2023) agreed that risk-stratified screening, for example, using genetic information would be useful, but noted possible challenges related to low-risk screening. This included providing false reassurance for patients and creating risks of blame or legal action if cancer does develop (Ayoub et al. 2023). In the case of pharmacogenomics, more than half of studies of pharmacogenomic testing in primary care suggest support for implementation, with perceived benefits relating to improved outcomes, precise treatment allocation, a decrease in adverse drug reactions and improved adherence to treatment (Mai et al. 2024).

Previous evidence also provides a variety of information on HCP perspectives towards effective education and training for the use of genetic information in practice. Across the studies reviewed by Dunlop et al. (2025), education was seen as a key approach to capacity building. Among 159 UK GPs surveyed by Evans et al. (2020), online primary care-focused resources were seen as particularly valuable. HCPs see tailored educational programmes as key to the use of genetic information in healthcare, including initial education and upskilling or reskilling. The NHS England Master's in Genomic Medicine framework programme was seen as highly valuable, which included a curriculum focussing on science, ethics, and practical applications of genomics (Nightingale et al. 2025). These HCPs also saw multi-professional cohorts for learning as a net positive, enabling learning across different parts of the health service (Nightingale et al. 2025).

Several factors are important for effective training, including a range of delivery formats for training. HCPs in two different papers highlight the utility of online courses and webinars as possible formats for continuous education (Lapointe et al. 2022; Kenneson et al. 2025). Nonetheless, some HCPs value a blend of face to face and online learning, combining the benefits of in-person interaction with the flexibility of remote learning (Nightingale et al. 2025). Moreover, as highlighted by Do et al. (2025), communities of practice can support the incorporation of genomics into healthcare. In the case of genetic counselling, for example, peer engagement has been shown to support co-learning and sharing across different roles, supporting problem-solving and helping HCPs to better understand the broader context associated with the implementation of genomic medicine (Do et al. 2025).

Capacity to engage with genomics education and genomic medicine is a persistent system level concern. While HCPs may feel they have access to genomic education programmes, they may not feel that they have time to engage with them. HCPs are concerned about their capacity to engage with education, highlighting institutional pressures that may make it challenging for them to participate in genomics education (Nightingale et al. 2025). Marlowe et al. (2025) note the concerns of community paediatricians in England surrounding the time it may take to engage with genomic medicine (both education and delivery), including workforce support, as well as the possible trade-offs between genomic medicine and other priorities (Marlowe et al. 2025).

The Genomics England literature review and other available evidence generally show that HCPs have positive attitudes towards the potential of genetic and genomic information in healthcare, but there are also concerns and key areas for consideration if/when deciding to implement this into practice.

1.3. Context of this project

In this context, RAND Europe, in partnership with Hopkins Van Mil, The Social Agency, People Street and The Leap, were commissioned by Genomics England to deliver the Genomics, Healthcare, and You engagement programme. This engagement programme aimed to understand public and HCP perspectives and views on using genomic testing and information into healthcare settings in England through an adult population genomics programme.

The programme includes three key workstreams – in-depth community-based engagement with potentially underrepresented or excluded populations across three locations in England, a wider public dialogue, and engagement with HCPs working in adult population healthcare outside traditional clinical genetics services. RAND Europe led the HCP engagement, and this document provides our final report for this aspect of the programme. The focus of this part of the engagement was to explore HCPs' views on using genetic information in their day-to-day roles, with ultimate aims to inform Genomics England's future adult population genomics research programme. Aspects explored included the utility genetic information could have, the potential impact on patients and their own roles, and information or support needs for using and implementing genetic testing and information.

1.4. Structure of this report

This report provides the findings from the HCP engagement. The structure is as follows:

Chapter 1 provides an overview of the report, placing the adult population genomics research programme and the Genomics, Healthcare, and You engagement programme in context.

Chapter 2 details our methodology and approach to the HCP engagement, including considerations on strengths and weaknesses.

Chapter 3 presents the findings from the HCP engagement and includes both thematic and role-based insights. Findings are provided across the following areas: impact on professional role and identity; utility and value; infrastructure and system needs; information and support; impact on patients; access and equity; consent and data access.

Chapter 4 includes a discussion of our findings, in the context of the wider literature, alongside recommendations and considerations for what this means for the adult population genomics research programme.

2 Methodology

2.1. Overview of approach

The focus of the HCP engagement aspect of the Genomics, Healthcare and You programme was to explore HCPs' views on using genetic information in their day-to-day roles. To explore this, we conducted an online survey and ran two sets of workshops. When designing the data collection, we considered the findings from the literature in key areas to explore further. The HCP engagement focused primarily on professionals drawn from primary and community care settings (including general

practitioners (GPs), practice nurses, and community pharmacists) alongside family history clinical nurse specialists (FHCNS) who can play a bridging role between primary and secondary care. The engagement also aimed to recruit those delivering public health interventions and services. These roles were identified as potentially having a role in the use and/or return of findings in the future, but as having potentially different experiences and expectations of genomics. As such, we present findings at both the level of individual roles and at the overall HCP level.

2.2. Aims and research questions

The overall aim of the HCP engagement was to explore views on using genetic information in their day-to-day roles. To consider this aim, we sought to address the following research questions posed by Genomics England:

1

How do HCPs feel about returning genomic findings to people when there is uncertainty about the precise predictive nature of those findings?

4

What information and support do different HCPs think will be needed to support people to understand and decide how to act on their findings?

2

How do HCPs feel about the utility of genomic testing which could have multiple future uses for someone, including at point of need for clinical decision making, not all of which may yet be known?

5

How do HCPs think that returning genomic findings on future risk could impact on the people receiving results and on HCPs?

3

How do HCPs feel about their potential future role in returning findings and the role which digital tools could play in this?

6

Who do HCPs think should have access to people's genomic findings, in what circumstances?

2.3. Survey

The survey was designed by the RAND Europe team with input from colleagues at Thiscovery² and review from Genomics England. It was delivered and hosted by Thiscovery and circulated through their network, by email and social media to potentially interested groups including the Royal College of General Practitioners, Genomic Medicine Services, the Association of Directors of Public Health and local public health teams, and community pharmacy networks, and by direct contact with individuals working in primary care and public health. The survey was also disseminated through additional networks within the project team, including NHS England and other royal colleges. Due to the nature of recruitment, it is not possible to establish the exact numbers of people contacted.

The survey had two aims: to provide insights into levels of familiarity and confidence in using genetic information among a wider population of HCPs, and to allow us to efficiently reach a diverse range of HCPs interested in participating in the workshops, in terms of experience and familiarity with genetics, location, and professional role.

Survey questions asked about HCPs' familiarity with and use of genetic information, perceptions of its potential impact, and whether they would need support in using the information. Participants were asked about both anticipated benefits (for example personalised care, improved prescribing, and earlier diagnosis) and potential challenges (for example resource pressures and increased inequalities) associated with the implementation of genomics in adult population healthcare. Questions were a combination of closed and open-text responses, and it was anticipated to take 10 minutes to complete. Finally, the survey asked for demographic information to allow us to contextualise findings across the different HCP roles. Questions covered role, years of experience, region, age, gender, and ethnic background.

The full survey protocol is provided in Annex A.

2.4. Workshops

Workshops were recruited through purposive sampling, with professional role as the primary selection criterion. This approach was designed to ensure representation across the range of institutional positions and professional perspectives relevant to the study's aims, rather than to achieve demographic representativeness. Initially, workshop participants were recruited through the survey if respondents indicated that they would be interested in taking part. Further recruitment took place through direct outreach by email and on social media (for example LinkedIn posts) by RAND Europe, programme partners, and Genomics England. Workshops were organised in two phases, with a total of 13 workshops and three interviews conducted as part of the HCP engagement between December 2025 and February 2026. All participants provided informed consent to take part in the workshops and for these to be recorded. Workshops were guided by semi-structured topic guides which explored various aspects of our research questions. More detail on each phase of the workshops is provided in the following sections. Workshop protocols are provided in Annex B and Annex C.

2.4.1. Role-based workshops

The first phase of workshops involved one-hour workshops homogenous by HCP group (e.g. all GPs, community pharmacists, or FHCNS). Six workshops and one interview were conducted in this first phase, with two supplementary sessions with practice nurses taking place afterwards and two further public health interviews (total of 11 sessions). Each workshop in this phase lasted approximately 60 minutes.

Questions focused on role-specific impacts and thoughts around current and future use of genetic information within healthcare settings (for example for a GP during an appointment) and the impact this may have on the patients they interact with, on the health system, and

² Thiscovery is a digital research and innovation platform. For more information, please see <https://www.thiscovery.org/about/what-is-thiscovery>

on their own role(s). We also ran an online discussion board via Microsoft Teams with HCPs who could not attend the role-based workshops and asked the same questions.

2.4.2. Systems workshops

The second phase of workshops involved 90-minute sessions that brought together HCPs across a mix of roles (rather than being split into professional group). These workshops involved the same participants from the first round of workshops. Three workshops were conducted, with two follow-on sessions for people who could not join the other dates. At these sessions, representatives from Genomics England gave a brief introduction to the Genomics, Healthcare, and You programme and provided an opportunity to participants to ask Genomics England any questions before the workshop discussions took place. The workshops were run through concurrent breakout groups (due to the number of participants in attendance), followed by short plenary sessions to share feedback between groups.

A semi-structured discussion in breakout groups focused on requirements within current practice and at the health system level for the successful introduction of genetic information into adult population healthcare. This included questions around the need for changes to practice, training and skills, and differences or similarities between professional roles. The workshop also included discussions on the impact on patients, and any information or guidance needed to support them.

2.5. Analysis and reporting

To analyse the survey responses, all raw data was provided to the research team and analysed using descriptive statistics and role level sub-group analysis. Data was exported to Excel for analysis, where descriptive statistics were conducted. Where notable differences were apparent by sub-groups, a descriptive breakdown was also conducted (e.g. by role).

The free-text responses from the survey were analysed by drawing out key concepts from each response and grouping these into themes. Insights from the survey were then integrated into the wider qualitative analysis taking place with the workshop data.

For the workshops, each workshop was recorded, transcribed using Microsoft Teams, and had a dedicated note-taker(s) in attendance. All notes were reviewed, and all transcripts were validated before being imported into MAXQDA³. Transcripts were analysed and coded using a mixture of inductive and deductive approaches, to allow for any unanticipated concepts or themes to be identified. An initial coding framework was developed by the research team based on the research questions and aims of the project and iterated following a pilot coding by one researcher and discussion with the team. Coded data were then reviewed and summarised, with concepts organised under key themes. Throughout, the research team used memos where appropriate to note any additional themes or points of relevance which were also reviewed in the final analysis.

2.6. Ethics

This project was reviewed by the RAND Europe Research Ethics Committee (RE-REC), which operates in accordance with guidance set out by the Economics and Social Research Council and the United Kingdom Research Integrity Office. A review of the project and all data collection materials was conducted, and ethical approval was received in October 2025.

³ MAXQDA is a software programme which can be used for the analysis of qualitative and mixed methods data. For more information, please see: <https://www.maxqda.com/>

2.7. Reflections on the methodology and approach

Our approach to HCP engagement enabled us to capture a broad range of views from participants involved across our target roles and settings of primary care, community pharmacy, and public health with 131 complete survey responses and 50 HCPs participating in the workshops and/or discussion board. By engaging with a range of professionals in both the survey and workshops, the project was able to collect insights relevant across diverse healthcare roles, strengthening our findings.

The purpose of this survey was not to produce a representative sample of the broader HCP population. Our sample was broadly representative of the National Health Service (NHS) England working population (NHS Digital 2023). However, the engagement had a relatively small sample size and used descriptive analysis to explore the survey findings. This makes it challenging to draw representative conclusions and guarantee scalable findings across the wider population. A full breakdown of the survey sample is provided in the findings section of this report (See Section 3.1).

One notable challenge for the engagement was the timing of recruitment, which coincided with the busier winter months when NHS staff typically have increased workloads and additional pressures (Alarilla et al. 2025), potentially affecting participation rates and engagement. The rapid project timelines resulted in reduced notice and limited run-up time to workshops, which also may have prevented some eligible participants from joining the workshop sessions.

Recruiting ‘uninterested’ staff can also be a challenge in research in primary and community care settings, where intrinsic motivation and interest are important drivers of participation (Krebs et al. 2021). It is possible that the focus on ‘genetic information’ may not have resonated with those who did

not see immediate relevance to their work, despite the framing in recruitment materials. Additionally, the diffuse nature of public health provision in England led to difficulties defining precise public health roles and identifying specific groups to target outside those working in primary care, which added further complexity to both outreach and recruitment targets. In particular, much public health delivery takes place outside the NHS, in the private sector and/or commissioned by local authorities to provide specific services, presenting additional challenges in terms of both access and demonstrating the relevance of genomics. The provision of public health services outside the NHS may also have affected the visibility of the project.

This may also have been a challenge for other HCP groups, such as practice nurses. Our survey partner, Thiscovery, noted that some outreach methods (such as emails to GP federations and LinkedIn posts targeting interest groups) were relatively unsuccessful. This could be due to a lack of appropriate gatekeeper organisations or insiders to advocate, or again because the subject area felt niche or less relevant against other priorities.

2.7.1. Recommendations and learnings for engagement with healthcare professionals

A variety of strategies were trialled to ensure successful recruitment. However, given the challenges encountered, several lessons and reflections may be of value to inform Genomics England’s future work and engagement with HCPs. We outline these below:

- **Timing** should be considered carefully, avoiding periods where staff are likely to be busiest (such as during winter pressures), to maximise engagement and participation.
 - Alternative time options, give professionals more time to engage outside of clinical working hours.

-
- Further, engagement may be more feasible where it uses staff protected time. For example, protected learning time in primary care might be used for training sessions on genomics or engagement with the research study.
 - Allow for an **extended lead-up time** and plan engagement activities in advance. This can be through longer overall timeframes for engagement, for example longer than a few months, to enable forward planning and allow time for finding suitable days/times for HCPs.
 - **Recruitment avenues could be more direct**, for example, working through the NHS and building and/or leveraging partnerships with specific NHS teams and professional bodies would ensure greater visibility among relevant HCPs.
 - For public health, where services are not delivered in primary care, this will involve working with local authorities and private sector providers – potentially including large companies delivering these services across multiple areas.
 - Working with teams in **local areas**, rather than across the whole country, may help engagement – practice nurses and public health teams were the hardest to engage for this work, and may be more effectively engaged at a local level through single general practices, primary care networks, or integrated neighbourhood teams. However, this has the potential to create bias.
 - Engaging less familiar, interested or involved groups may require further **personalised outreach**, with **clear articulation of the relevance** to their specific roles and day-to-day work and how their involvement **may shape decisions**. This could be enabled by working with local champions or specific individuals within target roles or professional groups.
 - Offering a **mixture of participation approaches** enables more diverse engagement. Engaging less familiar, interested or involved groups is facilitated by having lower burden forms of engagement. For example, some HCPs only contributed to the survey, whilst others only attended workshops. Giving HCPs different ways of participating can encourage responses from a wider range of participants and meet the needs of different individuals, depending on what their capacity allows.
 - This includes both in-person, online, written, and/or other opportunities, quick engagement exercises (such as pulse surveys), one-to-one conversations, workshops and focus groups, or reviewing materials and sending feedback.
 - Clear boundaries and definitions of roles are needed within a sector that has overlapping responsibilities. For example, defining whose perspectives within public health engagement are most needed (such as public health directors within the NHS or local authorities, NHS primary care providers of public health services such as screening, health checks and weight management, or those involved in delivering services outside the NHS).

3. Findings

This chapter presents the findings across the survey and workshops with HCPs. Findings are presented at the thematic level, with specific role-based insights highlighted throughout. All findings below are from the workshops and survey with HCPs. Where relevant, we provide selected illustrative quotes from the workshops and direct free text responses from the survey.

3.1. Sample characteristics

A total of **176 participants** responded to the survey to some extent. To ensure we had a clear understanding of who participated to sufficiently contextualise the results and establish the breadth of the sample across the UK, we only retained responses for survey respondents who completed at least one socio-demographic question and at least one of the core questions related to genomics, resulting in 19 responses being dropped. A further 26 respondents only answered one demographic question, so these respondents were also removed, resulting in a final sample size of **131 participants**.

While the purpose of this survey was not to produce a representative sample of the broader HCP population, we aimed to gather some contextual information about respondents to better understand the diversity of perspectives captured. Encouragingly, the responses reflected a broad mix of participants, allowing us to capture a range of viewpoints.

The workshop participants were drawn from the survey sample and supplemented by direct outreach as discussed in the methods. In total, 50 HCPs participated in the workshops and/or discussion board. As final recruitment for the workshops took place through multiple avenues, and not all participants provided data on socio-demographics, full data is not available for the complete workshop sample.

3.1.1. Socio-demographics

Socio-demographic information about survey participants is presented in Table 1 below.

In terms of age, the largest group fell within the 40–49 age range (30%, n=39), closely followed by those aged 50–59 (28%, n=37). The smallest age bracket was the youngest, 18–29 (6%, n=8). 25 (19%) respondents were 30–39 years old and 19 (15%) were 60+. A similar pattern emerged when looking at years of (general work) experience, with over two-thirds of participants reporting six or more years of experience (68%, n=89). Overall, our sample had strong representation from older and more experienced HCPs, though there remains a reasonable level of representation from younger and less experienced respondents.

There was a noticeable gender imbalance in the sample, with a significantly higher proportion of women (76%) participating compared to men (21%). However, wider workforce demographics are also highly skewed towards women for many caring professions, with women making up the majority of pharmacists (62%) (General Pharmaceutical Council 2023), pharmacy technicians (85%) (General Pharmaceutical Council 2023), and nurses (87%) (NHS England 2025).

Approximately two thirds of our sample were White (69%, n=91) followed by Asian (11%, n=15), Black (7%, n=9), Mixed Ethnicity (5%, n=6), and Other Ethnicity (4%, n=5). This is broadly

comparable to the NHS workforce as a whole (74.3% White, 12.53% Asian, 7.4% Black, 2.1% Mixed, 3% Other; NHS Digital 2023). There was broad representation from different geographic areas. London was the most frequently selected location category (21%, n=28), closely followed by the East of England (19%, n=25) and the South West (18%, n=23). Regions from the North and Midlands regions were also well represented, together accounting for nearly one-third of respondents. For more detail see Table 1 below.

As described above, purposive sampling for the workshops focused on ensuring sample adequacy by professional role. As a result of the differing recruitment approaches, sociodemographic data were only collected for 27 participants, of whom 10 were aged 40–49, 4 between 18 and 29, 7 between 30 and 39, 4 between 50 and 59, and 2 over 60. 8 were based in the South West of England, 6 in the Midlands, 4 in the North East and Yorkshire, 3 in the East of England, 3 in London, and 1 each in the North West and South East. This partial demographic picture does not affect the analytical basis of the findings. Thematic analysis was conducted across role categories rather than demographic variables, and the interpretive claims made in this report are grounded in the professional perspectives that purposive sampling was designed to capture.

3.1.2. Professional roles

Participants represented a diverse range of professional roles. While the survey included a set of predefined role options, many respondents also described their positions using the open-text field. This included pharmacy roles (i.e. clinical, technicians), breast clinicians and specialists, secondary care professionals, (including surgeons, hospital pharmacists) and roles with specific genetic expertise (such as genetic counsellors).

To make the range of roles more manageable for analysis, we consolidated them into

four primary categories. This approach enabled clearer comparisons across professional backgrounds while still capturing the diversity of perspectives within the sample. They are as follows:

- **Pharmacy** (PHARM) – 26% (n = 34)
- **GP/Practice Nurse** (PN)/Public health (PH) – 25% (n = 33)
- **Clinical nurse specialist** (CNS) – 17% (n = 22)
- **Other** – 32% (n = 42)

The 'PHARM' group includes respondents working in pharmacy settings, including those in community pharmacy, pharmacy technicians, primary care network pharmacists, and integrated care board pharmacists, including medicines optimisation and management pharmacists. The 'GP/PN/PH' group includes GPs (n=27), practice or primary care nurses (n=3), and those working in public health (n=3). Given the small numbers of respondents who were practice nurses or working in public health, these roles are grouped for analysis and to reflect the overlapping roles of general practice staff, and their central role in delivering public health services such as screening, risk stratification, and lifestyle counselling (Allen et al. 2024; Fenton 2025). The 'CNS' group refers to clinical nurse specialists (CNS), including family history clinical nurse specialists (FHCNS), those working in breast clinics, and colorectal CNS. This group of nurses are primarily based in secondary care and more closely affiliated with genetics services. The scope of this role varies, but may involve running risk assessment clinics to assess cancer risk, providing health promotion and lifestyle advice, arranging screening and/or establishing eligibility for referral to clinical genetics services. Lastly, the 'Other' group includes all other respondents. This encompasses healthcare assistants, consultants, surgeons, patient administrators, genetic counsellors, clinical geneticists, and other business/clinical management professionals.

Complete professional role data was obtained for all 50 workshop participants. 17 participants were community pharmacists, 11 GPs, 10 FHCNS, 8 practice nurses, and 4 worked in public health.

Table 1 below provides a detailed breakdown of our survey sample's demographic profile, professional roles, and levels of understanding and use of genetics. Data are presented by question and response option, including both raw counts and percentages.

Table 1: Survey participant characteristics (n=131)

Variable	Category	Number	Percent
Age	18-29	8	6%
	30-39	25	19%
	40-49	39	30%
	50-59	37	28%
	60+	19	15%
	Prefer not to say	3	2%
Gender	Female	100	76%
	Male	27	21%
	Prefer not to say	4	3%
Region	East of England	25	19%
	London	28	21%
	Midlands	13	10%
	North East and Yorkshire	17	13%
	North West	11	8%
	South East	11	8%
	South West	23	18%
	Other	3	2%
Ethnicity	Asian/Asian British	15	11%
	Black/Black British/Caribbean/African	9	7%
	Mixed/Multiple Ethnic Groups	6	5%
	White	91	69%
	Other Ethnic Group	5	4%
	Prefer not to say	5	4%

Variable	Category	Number	Percent
Role	GP	27	21%
	Pharmacy	34	26%
	Public health	3	2%
	Practice nurse	3	2%
	Clinical nurse specialist	22	17%
	Other	42	32%
Experience	Less than 2 years	7	5%
	2-5 years	34	26%
	6-10 years	27	21%
	11-20 years	34	26%
	20+ years	28	21%
	Prefer not to say	1	1%
Use of genetics	Never	32	24%
	Rarely	23	18%
	Occasionally	23	18%
	Regularly	53	40%

To note, the total sample was 131, therefore, for each variable, the sum of all answers is equal to 131. Percentages may not sum to 100 due to rounding.

In the following section (Section 3.2) we provide overall survey findings. Further, we present role specific insights, reflecting differences between HCPs in training, differing interactions and involvement with patients, and whether or not their role would involve ordering genetic testing or delivering results to patients (Falahee et al. 2018).

3.2. Survey findings on the use of genetic information in healthcare

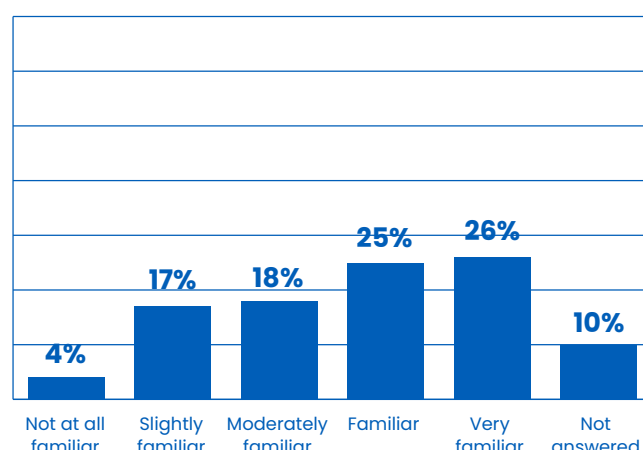
Box 1: Summary of survey findings on the use of genetic information

Across the HCPs who participated in the survey, most were familiar with genetics and considered it relevant to their roles, though those working in primary care and public health were less familiar than CNSs and others. Day-to-day use varied, with CNSs and some specialists using it more regularly than GPs and other roles. Confidence levels were generally high, but the majority still reported needing more training and practical support. Key anticipated benefits included more personalised care and accurate prescribing, but main concerns included patient anxiety, inequalities, and the potential for increased workload. Perspectives did vary by professional group.

3.2.1. Familiarity with and use of genetics

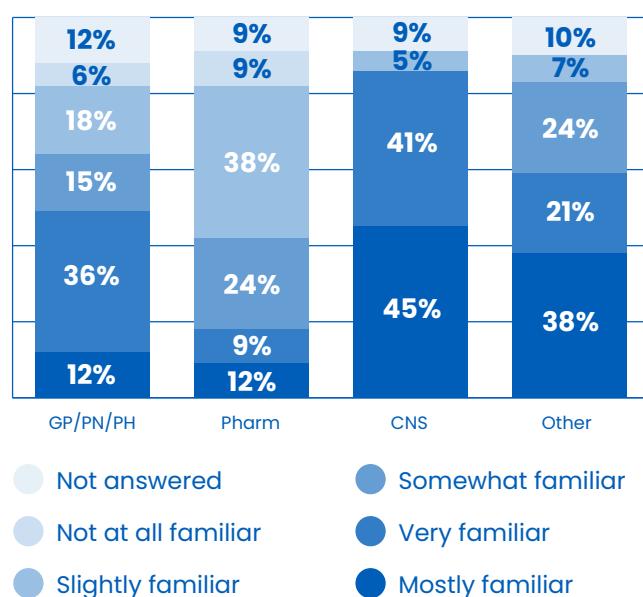
The survey asked participants about their familiarity with genetics and how frequently they used it in their professional roles. Our sample was relatively familiar with genetics, with only 4% (n=5) saying they were 'not at all familiar' and over half saying they were 'familiar' or 'very familiar' (51%, n=67). This is possibly not surprising, given those more familiar with the subject matter may have been more likely to participate in the survey. See Figure 1 below for a more detailed breakdown of this question.

Figure 1: Familiarity with the use of genetic information in healthcare (n=131)



There were notable differences in familiarity by role from the survey respondents, see Figure 2 below. The 'CNS' and 'Other' groups had a much higher proportion of respondents who selected 'very familiar' or 'mostly familiar' (45% and 38%, respectively) compared with the GP/PN/PH and Pharm groups (12% for both). This is unsurprising, as the 'CNS' and 'Other' categories largely include roles where genetics features more prominently, whereas for GPs and pharmacists, genetics typically represents only a small part of their work.

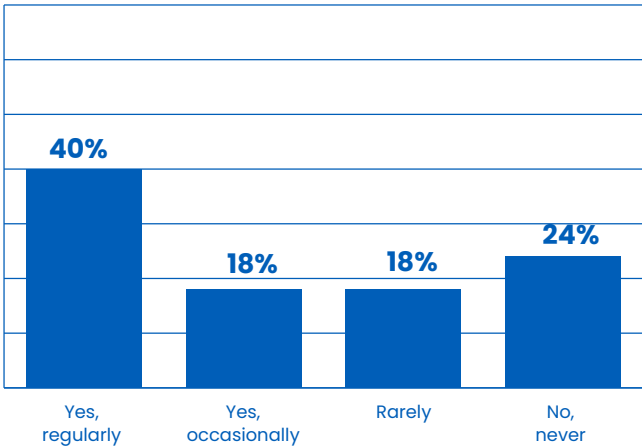
Figure 2: Breakdown in familiarity with the use of genetic information in healthcare, by role (n=131)



Among the 24 workshop participants who completed the question on familiarity, 7 were very familiar, 6 mostly familiar, 4 somewhat familiar, 6 slightly familiar, and 1 not at all familiar.

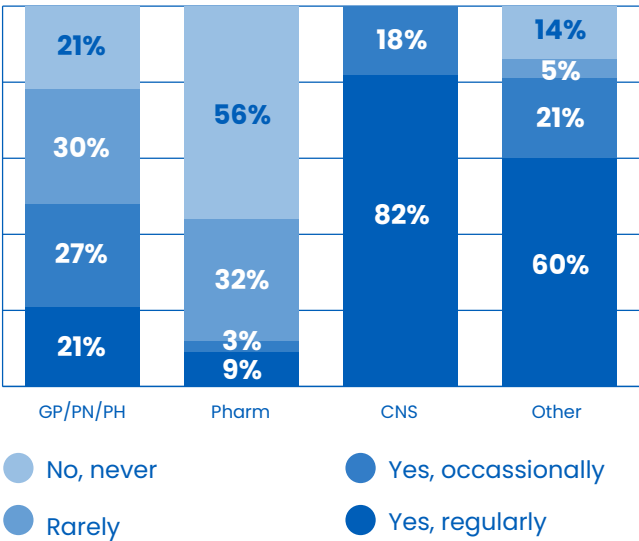
Overall, more people said they used genetics in their day-to-day role compared to those that didn't. The most common respondent profile was someone who reported using genetics regularly (40%, n=53). 24% (n=32) said they never used genetics in their work, 18% (n=23) said rarely and 18% (n=23) also said occasionally. Interestingly, this means our sample was quite balanced with people reported rarely or never using genetics (42%, n=55) and people who used it regularly (40%, n=53). See Figure 3 for more detail.

Figure 3: Use of genetics in day-to-day work (n=131)



We also looked at how day-to-day use varied by role type; a significantly higher proportion of 'CNS' (82%, n=18) and 'Other' (60%, n=25) respondents reported using genetics regularly in their day-to-day work compared with the GP (21%, n=7) and the Pharmacy (3%, n=3) groups. All respondents from the 'CNS' group reported using genetics 'regularly' or at least 'occasionally', which reflects the nature of the role. See Figure 4 below.

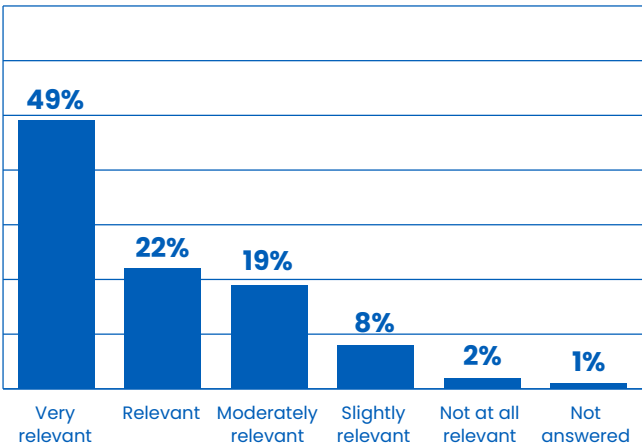
Figure 4: Use of genetics in day-to-day work, by role (n=131)



3.2.2. Relevance of genetics

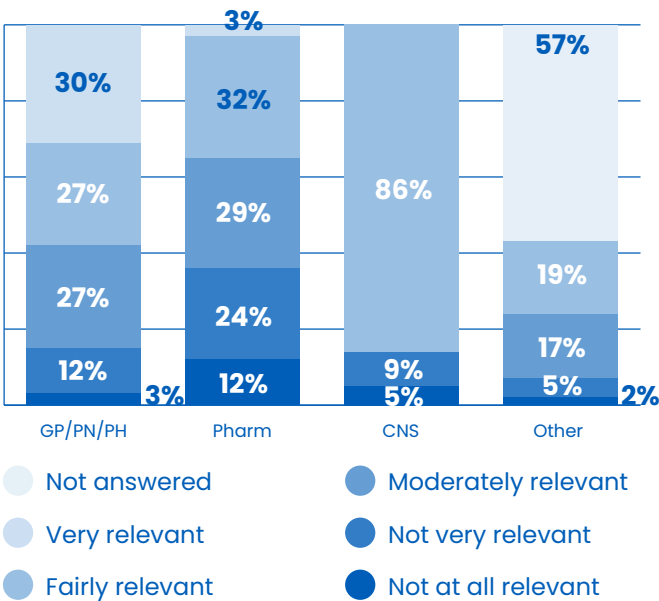
When asked how relevant HCPs would find genetics to their roles, only **2% of respondents** said it was **not at all relevant**, while just under half (49%) rated it as very relevant, see Figure 5 below. This suggests that, even though a substantial minority of participants reported not using genetics in their day-to-day roles (see section above), the perceived **importance and relevance was much higher**. In other words, several respondents considered genetics to be relevant to their work, even if they were not currently applying it in practice.

Figure 5: Relevance of genetic information to your role? (n=131)



In terms of relevance to their roles, the pattern was again similar. People from the ‘CNS’ and ‘Other’ groups were far more likely to select ‘Very relevant’ (86% and 57% respectively), compared with the GP/PH/PH and Pharm groups (30% and 32%, respectively).

Figure 6: Potential relevance of genetic information to role, by role (n=131)



Regarding use of genetics in day-to-day work, as described earlier (Section 3.1), participants were asked to provide further detail on how they used genetic information in their role via an open text box. Responses included examples of use across family history and stratifying risk, alongside making referrals (i.e. for cascade testing).

It would usually involve discussion on referring for genetic testing with red flag hereditary patterns

Open text survey response

I do genetic mainstreaming work as well [as being] involved in the clinical genetic referrals for family history patients

Open text survey response

We ask about family history of cardiovascular events before the age of 60 to help us to calculate the QRISK. We refer patients with high cholesterol levels for genetic testing to diagnose familial hypercholesterolaemia and they can be offered biologic treatment.

Open text survey response

Other examples included involvement in genetic testing (i.e. ordering tests, giving results), use for patient management, and supporting other HCPs.

I work both as a GP and GPwER [GP with extended role] in genomics. In the GPwER role it involves ordering testing and delivering test results. This includes array testing, panel tests, whole genome sequencing and research results.

Open text survey response

Assessment and management of patients with breast cancer, assessment and management of people at risk of breast cancer

Open text survey response

I provide advice to other healthcare professionals about accessing pharmacogenetic testing for their patients, or to help with interpreting results in the context of the individual clinical scenario

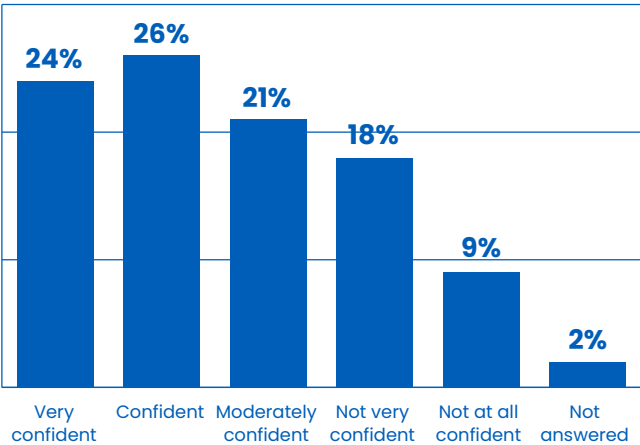
Open text survey response

3.2.3. Confidence and support needs

We asked participants how confident they felt in supporting patients to understand genetic information, and how much training or support they would need to do so.

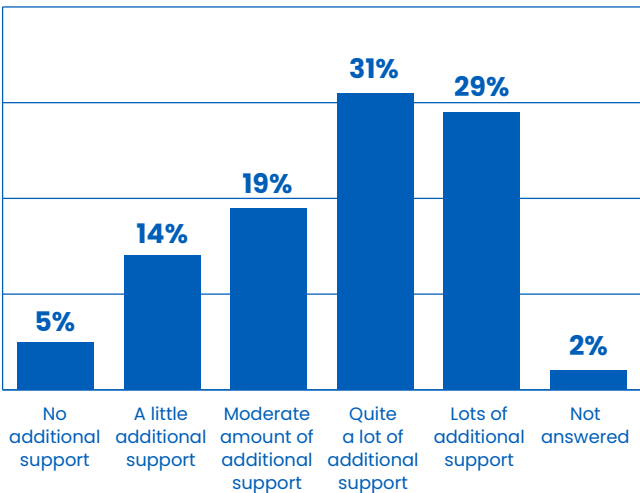
Half of respondents (50%, n=66) said they would feel ‘confident’ or ‘very confident’ supporting patients with genetic information, while fewer than one-third reported low confidence (9% said they were ‘not at all confident’ and 18% responded as ‘slightly confident’). This information is presented below in Figure 7.

Figure 7: Confidence in supporting patients to understand and use genetic information (n=131)



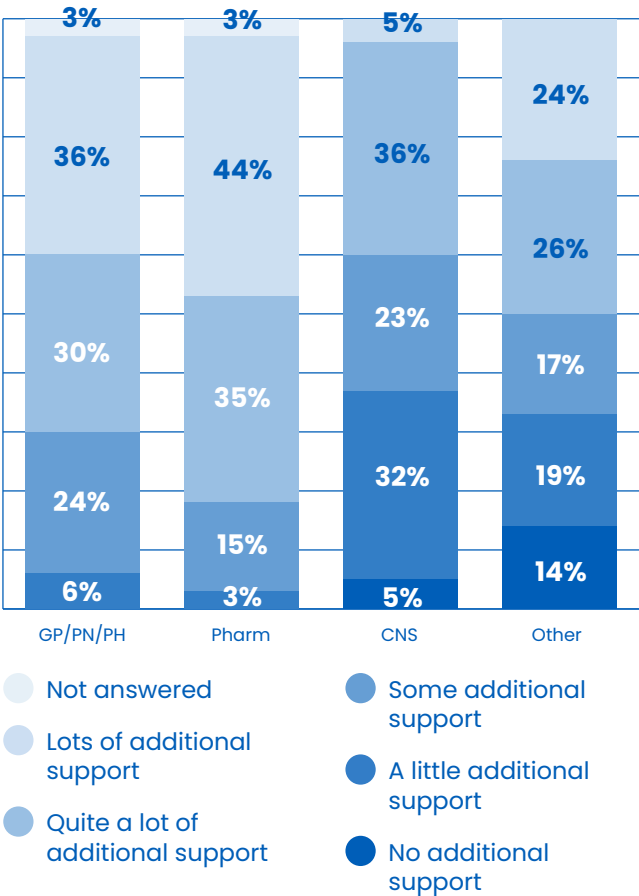
However, despite these relatively high levels of confidence, most respondents selected one of the top two high support-need options (60%, n=79), as shown in Figure 8. These findings suggest that while participants may feel confident in principle about supporting patients with genetic information, they still recognise the need for practical training and resources to apply this effectively in real-world settings.

Figure 8: How much additional support respondents would require if genetic information was included in the care they provide (n=131)



When broken down by roles, although the ‘CNS’ and ‘Other’ groups were generally more familiar and viewed genetics as more relevant to their work, there was less of a clear divide when it came to support needs. Within each of the four professional groups, most respondents indicated that they would need ‘some’, ‘quite a lot’, or ‘a lot’ of additional support, compared to ‘a little’ or ‘none’. The ‘CNS’ and ‘Other’ groups were the most likely to say they required no support or only a little support, compared with the GP/PN/PH and Pharm groups. This again reflects the earlier finding that, despite varying levels of confidence and familiarity with genetics in theory, there remains a consistent demand for practical support and training to apply this knowledge effectively in practice. A more detailed breakdown is provided in Figure 9.

Figure 9: Support that would be needed, by role (n=131)



3.2.4. Positive and negative expectations

In this section, we draw on the survey findings to describe positive and negative expectations of HCPs towards the more widespread use of genetic information in adult population healthcare. This includes understanding how HCPs feel about the use of this information in contexts of uncertain predictive value and utility.

Positive expectations and hopes

The survey asked respondents about what they considered to be the most positive and negative things to result from using genetic information in healthcare over the next five years. Here, participants were able to select up to three response options (for both positive and negative aspects) so results will not add up to 100%.

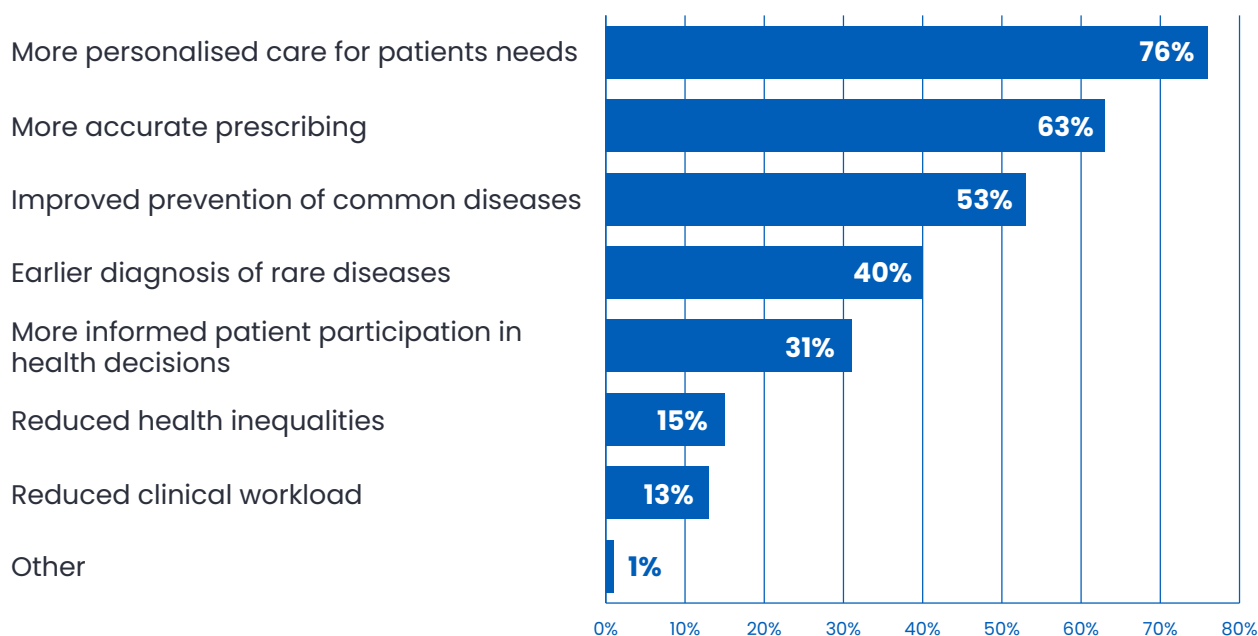
In terms of positive outcomes, the most frequently selected response was “more

personalised care for patient needs” chosen by over three-quarters of participants (76%). Other popular responses, each selected by more than half of participants, included “more accurate prescribing” (63%) and “improved prevention of common diseases” (53%). None of the provided response options were selected by less than 13% of respondents, indicating that all the outcomes were viewed as beneficial to at least some extent. Open text responses on positive outcomes including increased empowerment and informed decision making, resource and cost efficiency, alongside emphasis of the response options provided.

It will save time in making prescribing decisions that are otherwise ‘educated guesses’. It will give both patients, their families and the doctor more information that they can share and discuss to reach a common understanding.

Open text survey response

Figure 10: Most likely positive outcomes of using genetic information in healthcare in the next 5 years (% that selected outcome in top three) (n=131)



To note, respondents could select three answers each, so they do not sum to 100%.

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

Open text survey response

It will reduce wasted resources in terms of money and time prescribing the wrong drugs to the wrong patients.

Open text survey response

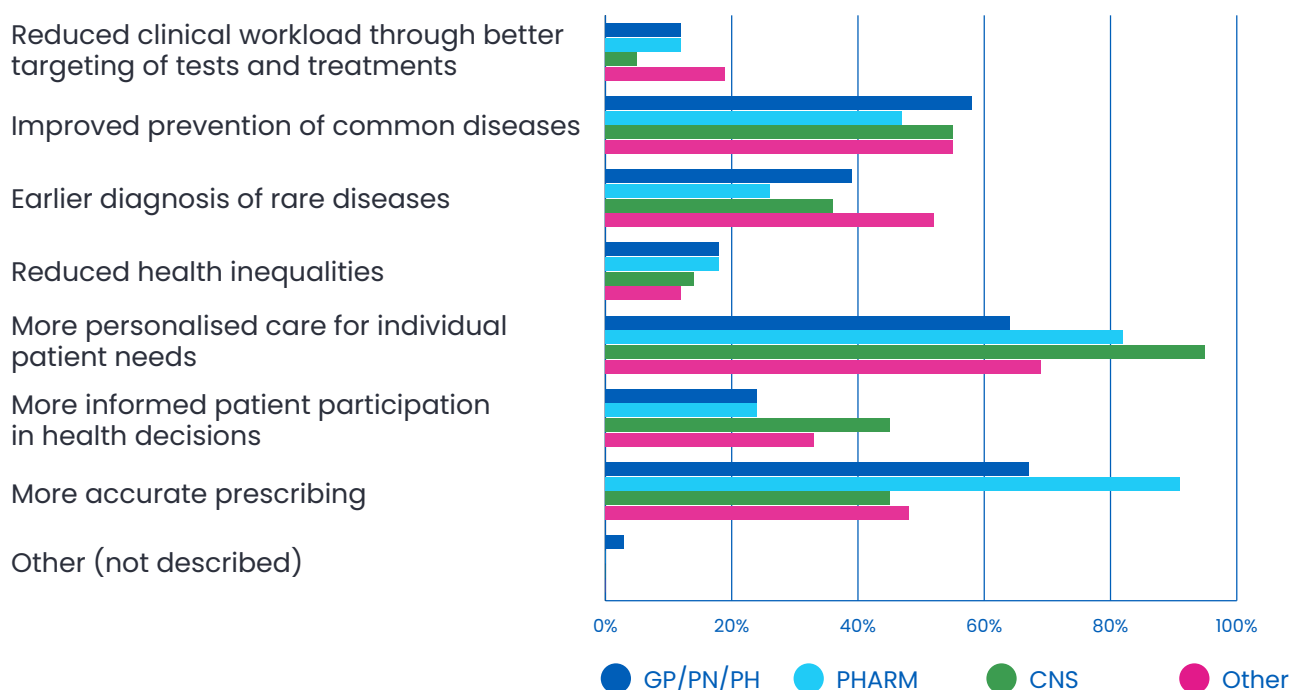
There was some variation across survey respondents in the responses to this question by role, with some interesting differences that emerged between professional groups.

A similar difference was seen among the CNS and pharmacist groups; 91% of pharmacy respondents selected “more accurate prescribing” as a key positive outcome, compared with only 45% of the CNS group, perhaps reflecting the focus of the pharmacy role.

Negative expectations and concerns

As with positive expectations, respondents were asked what they considered to be the most likely negative consequences of using genetic information in healthcare over the next 5 years. Participants were able to select up to three response options. The most frequently selected potential negative outcome in the survey was “increased patient worry and concern” (60%). The least frequently

Figure 11: Most likely positive outcomes of using genetic information in healthcare in the next 5 years, by role (n=131)



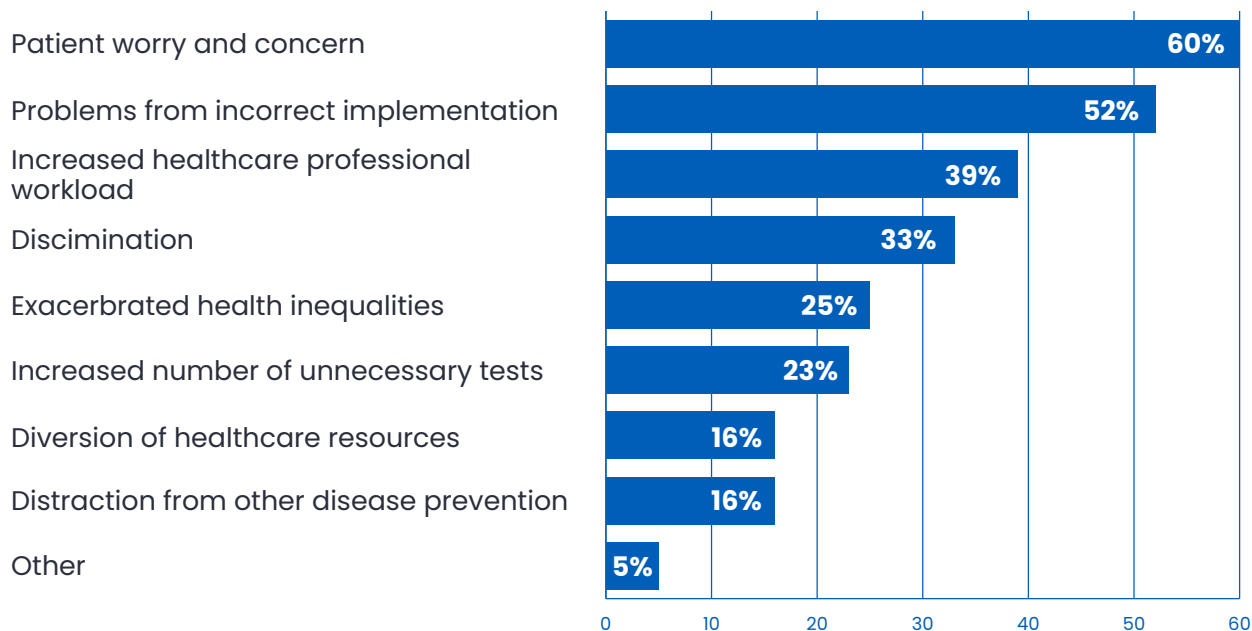
NB: Respondents were able to select three answers, so they do not sum to 100% by role.

This is broken down in Figure 11 below. Among the CNS group, almost all participants (95%) selected “more personalised care for individual patient needs” as one of their top three positive outcomes – the highest proportion across all roles. In contrast, fewer than two-thirds of GPs selected this option.

selected were “Diversion of healthcare resources” and “Distraction from other disease prevention efforts” (both 16%).

Please see full breakdown of responses in Figure 12.

Figure 12: Most likely negative outcomes of using genetic information in healthcare in the next 5 years (n=131)



To note,; respondents could select three answers each, so they do not sum to 100%.

Open text responses on negative outcomes highlighted a range of concerns, including emphasis on the risk of increasing health inequalities and risks around data misuse and privacy.

It will all depend on how the genetic information is stored, and used, and who has access to it. Health inequalities are likely to be increased as those with lower health literacy are less likely to access genomic medicine. There are always unforeseen consequences to new developments, so it is possible that resources will be channelled away from current priorities.

Open text survey response

Genetic knowledge is likely to be used to profile people and could affect employability, health insurance, travel insurance and impact reproductive choices. It could also have a negative mental health impact. All of this with a very imperfect knowledge by public and many clinicians of genetics, how genes interact and how statistics work

(e.g. what does 40% increased chance mean when baseline chance is 1% etc.)

Open text survey response

Survey respondents emphasised the risk of increasing patient worry, with potential added anxiety and mental health impacts.

My largest concern, however, would be the emotional impact on patients. While this could indeed be a breakthrough for people's physical health, it could generate more need for mental health teams. (...) Retaining empathy and remembering the entire purpose of all of this is to benefit people – not money, not status, not control – needs to be at the heart of any healthcare breakthrough such as this.

Open text survey response

It could lead to additional patient worry, for example about a condition that they may be more likely to develop and this could impact on a person's mental health, in extreme cases, increasing suicide risk or risky behaviours.

Open text survey response

Some also noted the challenges of incidental and/or uncertain findings and the impact this could have on patients.

The more testing that is done, the more we find incidentals or variants that are difficult to understand and interpret. Staffing in molecular and clinical genetics is already stretched and it takes a long time to train and recruit suitable staff. There is a risk of clinicians in other specialties misinterpreting results if they do not have adequate support from genetics services.

Open text survey response

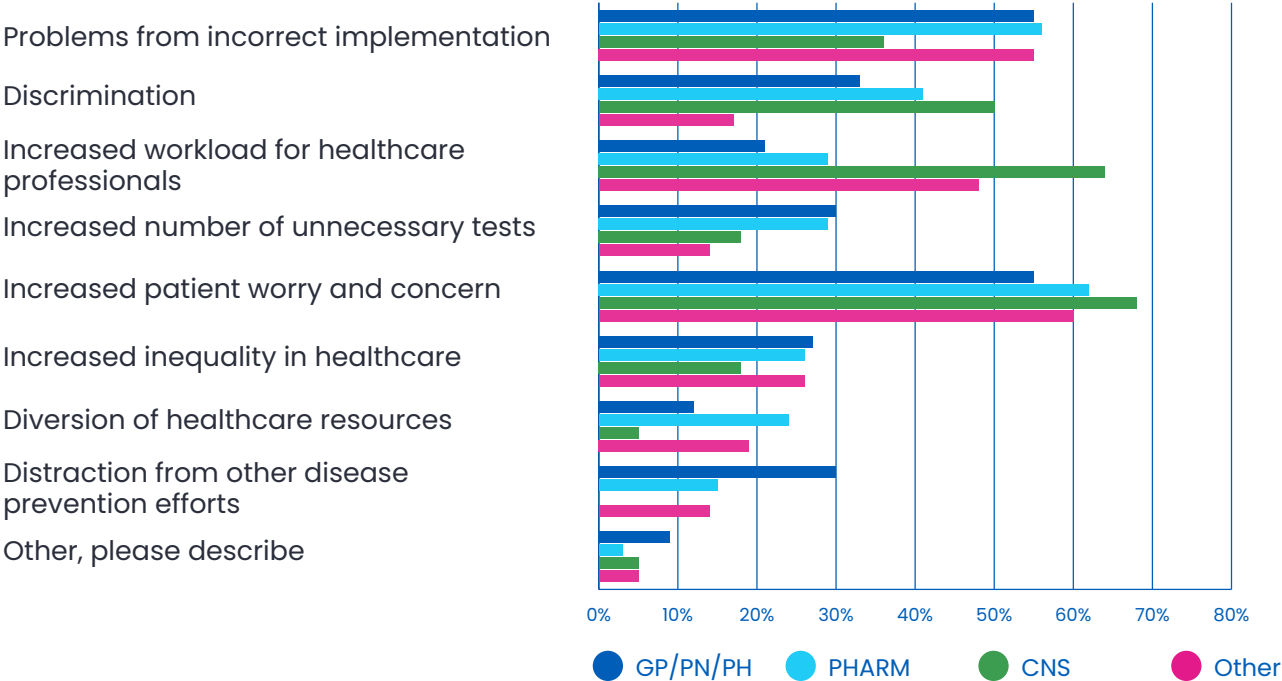
I think it's possible things will be detected that have an uncertain significance which may then cause anxiety and possibly unnecessary tests.

Open text survey response

Other negative impacts shared in the survey were concerns on increased strain on the workforce, alongside current lack of training and knowledge gaps.

As for positive expectations, there were differences between roles when selecting negative outcomes. For example, around 64% of the CNS group identified “increased workload for HCPs” as a key concern, compared with only 21% of GPs. In contrast, GPs were more concerned about “distraction from existing and effective disease prevention efforts” (selected by 30% of GPs). This was a much lower priority for CNS respondents, with not a single respondent from this group choosing this option (n=131). Figure 13 indicates most likely negative outcomes of using genetic information in healthcare in the next 5 years, by role.

Figure 13: Most likely negative outcomes of using genetic information in healthcare in the next 5 years, by role (n=131)



To note, respondents were able to select three answers, so they do not sum to 100% by role.

These findings highlight clear differences in perspective between professional roles – particularly between GPs and CNSs – in how they view both the potential benefits and challenges of integrating genetics into healthcare practice.

Workshop findings

In the following sections, we present the findings of the HCP workshop discussions. These are discussed in seven sections considering HCP views on their potential role in working with genetic information, the perceived utility and value of this information, and considerations of infrastructure and the readiness of the health system, information and support needs, and the impact on patients. Finally, we consider how questions of access and equity were raised by HCPs, and questions related to data access, storage, and consent.

3.3. Impact on professional role and identity

Box 2: Summary of healthcare professional views on professional role and identity

Across healthcare professionals, there were mixed views on how integrating genomic information would impact their roles. Some had **concerns around workload and workforce pressures**, but some acknowledged potential **for positive evolution in their roles**.

In this section we consider how healthcare professionals feel about their potential future role in returning genetic findings associated with disease risk (monogenic or polygenic) or pharmacogenomics.

3.3.1. Changes to roles and impacts on healthcare professionals

In workshops, HCPs reflected on the potential introduction of genetic information into their roles, and the impact this could have. As discussed above, genetic information was seen as more relevant for some roles than others – notably for the FHCNS group – and pharmacists were less likely than the other groups to currently use genomics in their day-to-day work.

In workshops, one area of discussion was the potential **impact on day-to-day work and workload**. Noting current workforce pressures, some HCPs, notably the FHCNS groups, highlighted that this would add onto their already high workload but others, particularly community pharmacists, shared that not much would change. Some HCPs also noted that while workload may increase initially, over time the use of genomics could lead to efficiencies and time saving.

I personally don't think a lot would change in my day-to-day because I do a lot of clinical documentation for GP surgeries and all of the blood tests, receive the blood tests, recommend changes based on blood. So to me that wouldn't really change (...) it's just something else to consider.

Community pharmacy workshop 2

So sort of keeping the idea of (...) saving time and sort of overall resources, I think my brain goes to probably the much more longer term such as things like taking pressures off of say more advanced clinicians (...) so it could be trickled down to different professions or other people, meaning that it frees up those so more advanced practitioners or GPs.

Community pharmacy workshop 2

Without really upping the capacity of more staff, which, you know, you're fighting a losing battle on that front, everybody's got to kind of just do as much as they can within the time and the role that they've got.

FHCNS workshop 1

Not everybody can do everything, which is why it sort of becomes down to specific roles for certain individuals really. In an ideal world, yeah, you'd have such a massive team that several people could all do the same role. But you know, we're far from that, aren't we?

FHCNS workshop 1

HCPs discussed how their roles would evolve with the use of genetic information, with some **shifts or expansions to their responsibilities**. There were mixed views about whether this was positive or negative, with some noting the benefits of their expanded role versus others questioning how this would fit with their existing roles and the need for prioritisation. The FHCNS groups suggested that their role may not change significantly but emphasised the need for better recognition for their role.

If you introduce any new services, the first question GPs will ask, I suppose all other professions as well, what do you want me to stop to do this extra work? (...) if it's a new service without, you know, any new funding.

Systems workshop 1

I think actually recognising it as a role would be the biggest thing in our Trust because I'm doing it ad hoc to my normal CNS role, you know, and it's really difficult because I could almost do that full time on a busy week and especially the family history side.

FHCNS workshop 1

There were mixed views on the level of **comfort with changes and increases in responsibilities**, with some noting reluctance to new programmes or interventions within their services. Other HCPs shared excitement, noting a need to overcome existing barriers (including the need for training).

As somebody who worked as a breast CNS, there were a lot of barriers, the genomics and the family history and the genetic testing was almost kind of seen as something quite scary. People were reluctant to get involved in it.

Systems workshop 2

I think there was a bit of excitement around you know what genomics could actually do in, in day-to-day practice (...) but there was also a lot of cautiousness around the ethical implications for us.

Systems workshop 1

3.4. Utility and value

Box 3: Summary of healthcare professional views on utility and value

Healthcare professionals provided examples of current use of genetic information. These included using genetic information to **guide prescribing, tailor treatments, and support screening and risk assessment**. Future potential was highlighted in opportunities in more **personalised, efficient, and preventive care**. Concerns raised included lack of guidelines, complexity and uncertainty, and patient worry regarding results.

In this section, we examine how healthcare professionals in the workshops discussed the potential value and utility of genetic information, for example, where these may be associated with risk identification and pharmacogenomics but evolve over time.

3.4.1. Current uses

HCPs offered examples of current uses of genetic information in their roles and settings. The examples shared reflected how genetic information is used in a variety of ways, such as testing patients to prescribe the right medication, to tailor a specific treatment to the patient's particular needs, or to have access to the patient's genetic history and be able to identify specific characteristics for a consultation. Some HCPs had also been involved in previous studies and pilots.

I've been involved in a pilot study using pharmacogenomics (...) in my own surgery and I have offered pharmacogenomic testing to patients when I've been prescribing with things like (...) antidepressants and opioids and (...) it's so interesting when the result comes like even me with all the (...) knowledge and like enthusiasm, confidence etcetera.

GP workshop 1

We do something called an oncoType to work out the benefit of chemotherapy and that's kind of looking at genetics and that of the actual cancer tumour. So you know treatment as it's becoming more and more individualised and specifically targeted is going to be really based on [the] whole of genetics of either the person's DNA or the cancer genetics

Systems workshop 4

In current use, HCPs identified the value of explanations in helping to manage the use of genetic information for patients.

When we get some (...) genetic bloods, they give you a paragraph of what you need to be doing with the information. So things like that [are] really helpful.

Practice nurse workshop 2

I think so our clinicians are really keen to get on and do testing and where the guidance is available.

Systems workshop 2

They suggested that existing guidelines and tools, like QRISK, could be a valuable model for how this might work.

I mean just from a practical perspective, when we, you know, prescribe something or we see a patient, we get a pop up and it says this person has got high frailty risk or you know for example to run the QRISK on somebody that you've just had a cholesterol back.

GP workshop 2

We use SystmOne in our GP practices in a lot of London and the QRISK2 (...) [which] is the one that's embedded into the electronic patient care record. So if when we file a blood test result, the risk is automatically calculated.

Systems workshop 1

However, HCPs also described some challenges associated with the use of genetic information when facing specific cases of patients who are either worried about the results, or where there are other possible consequences associated with a specific treatment. This included patients who object to either being tested themselves or have family members tested, for example in the presence of familial conditions.

We've had one that's (...) a family has a history of Huntington's that didn't want to be tested because they felt like it was just a life sentence, and we've had also a sibling of someone with quite a strong family history of the BRCA gene not wanting to get his daughter tested because he didn't feel that that was appropriate, so it's just quite hard to know, isn't it, when you would think that people would be quite keen, but we have had a few that have declined.

Practice nurse workshop 2

In other circumstances, HCPs highlighted situations in which a treatment is available, but the personal circumstances of the patient preclude this being implemented, decreasing the value of the genetic information at that time.

There was a patient that I spoke to not long ago and she's of, like, childbearing age in the 30s, but she's got an extremely high cholesterol and she's been screened for familial hyperlipidaemia, but she's of childbearing age and she wants to start a family, but she's never [given] a set kind of timeline as to when. So that's kind of a case where I think it's not(...) been massively helpful because she's not going to go on statins if she wants to get pregnant and have a family. But that's kind of a case where it [genetics] wasn't particularly, it's not been extremely helpful.

Practice nurse workshop 2

Another area identified by HCPs was the limitations of current approaches to the use of genetic information. As discussed further in Section 3.6, one common limitation highlighted was the **lack of guidance or protocols** that would allow HCPs to access **accurate and consistent information to inform decision-making**. Moreover, they expressed a concern about patients who present in pharmacies or clinics with **genetic information from private providers**. These results do not have clear explanations or the level of detail necessary to be interpreted during a consultation and present a cautionary comparator for increased access through the NHS.

It's not very helpful when they come with the private test and they just see what they've got, but no interpretation of the actual clinical significance or guidance about what to do next.

Community pharmacy workshop 2

In other cases, HCPs described how existing healthcare pathways may limit either access to genetic information, or the use of this information, leading to missed or delayed identification and treatment of patients.

I do a bit of work in an endocrine clinic and we have quite a lot of genetic high cholesterol and at the moment you've got to jump through quite a lot of hoops to get to an endocrinologist to get that genetic testing, to see whether it is true, genetic, high cholesterol and obviously those people are much more at risk of heart disease, cardiovascular disease at a much earlier age. So you know, at the moment there's no routine testing for do we need to start treatment early.

Practice nurse workshop 1

I've noticed where I've worked [with] a massive divide in what they sort of want you and allow you to do with sort of statin initiation, blood pressure titration. Some have really good protocols in place for us to follow, whereas some are just like, no, you're not like touching that, which I think it just depends on the workplace.

Community pharmacy workshop 2

Others highlighted that they did not use genetic information or genomics at all within their current work, perhaps reflecting the nature or focus of their work and roles.

We don't, like, genomics never came up in the five years I was in public health at any point.

Public health 2

3.4.2. Future potential and value

HCPs views on future potential of applications of genetics emphasised the potential to streamline screening processes and predict risk, or to support with prescribing, reduce wastage and increase awareness of potential side effects.

This is just an extra an even better way of screening people. Alongside screening programmes that we've already got, then potentially it could, you know, end up ruling out (...) the more (...) old fashioned screening programmes and we might not need to do that if

We're already you know if we can do a screening programme in genomics that covers everything say.

Practice nurse workshop 1

I think the overall impact of if we can reduce the, if we can select the right medication the first time round, the impact that that might have on wastage and general like loss of money because of wastage. I mean, I worked in like primary care, hospitals, GP surgeries, you see it everywhere.

Community pharmacy workshop 2

It will be really useful to know what sensitivities a patient will have for which drugs they're taking. There will be amazing searches I could run and and sort people's medication out. That would be really, really helpful.

GP workshop 2

Many professionals shared that utilising genomic information could help shift from reactive to proactive treatment approaches and work alongside existing workflows and information. The prospect of having more precise tools or information to guide decision-making and/or predict risk was also motivating for HCPs.

I was just thinking that in terms of prevention, it's really exciting because often, you know, in primary and community care and we're sort of reactive. So I think this is really exciting that we can be, you know, using it as a tool put together with some of our other tools to kind of use it more in prevention and obviously for us and for the patients, that's really beneficial.

Systems workshop 3

I suppose that's more the mainstream old fashioned general practice where you're reacting to people coming in to see you rather than proactively thinking about genomics and how it might help your practice population.

GP workshop 2

In terms of the value for decision-making, HCPs saw the use of genomics as a facilitator to make more informed decisions themselves, but also to help patients in doing this. This includes having enough information to make decisions in their roles, as well as communicating to patients the necessary information so they can decide about their potential treatments or how to engage with and/or manage their genetic predispositions.

Positive is getting things diagnosed at an earlier point and being able to manage whatever the condition is and it's giving them the ability to have that knowledge, which is, you know, that power to be able to make positive decisions throughout their lives that might reduce their risks.

Practice nurse workshop 2

HCPs also shared other views on potential for the future, such as preventing trial and error prescriptions or producing information to do the right screening, saving money and time for both the patient and the system. Many professionals highlighted the benefits of being able to match and prescribe patients with the most effective medicine the first time, potentially improving the patient-healthcare professional relationship. Additionally, HCPs talked about how genetic information would facilitate engaging the patient in deciding what medication or treatment would work better for them by providing them with a genetic explanation for their particular circumstance and increasing the likelihood that they would persist with treatment.

So you know, matching people to the right drug saves money, which is always a big thing for the NHS. But you know, it's a lot of time and pain for the patient to be on the wrong drug and keep swapping and that and they lose hope with it. And you know, they give up quickly when they perhaps wouldn't do that.

Systems workshop 4

It saves money for the NHS and the screening programmes they could, you know, it might be the other screening programmes can have more investment because they can't be done through genomics maybe.

Practice nurse workshop 1

I think it could be massively helpful in terms of getting patients to engage if you could sort of give them almost an insight into how you know which medication is going to work best for them. Then I think maybe they would be more willing to engage. If you can say, oh, we know that you'll you're not going to have as you know as many side effects with this medication as this one, this one will suit you best, then I think maybe they would be more willing to engage.

Community pharmacy workshop 2

However, HCPs highlighted the complexity and uncertainty involved in genomic testing and interpretation of information. Unlike traditional tests that may deliver clear results, HCPs noted that genetic findings can sometimes be ambiguous, nuanced, and open to interpretation. The clinical significance of some variants remains unclear, which could lead to challenges in interpreting results, making clinical decisions, and counselling patients. Other HCPs raised challenges of different understandings or awareness levels in how genetics is and can be used within healthcare.

My other thought about this is as a clinician sitting with your patient in front of you, it's going to, it's going to be another tool, but it's going to add another layer of complexity to the decision making when you're making that decision. And then yes, you might have appointments further down the line, but I can imagine things will start moving quite quickly at some point in terms of updates and new guidelines and new

information. So I think it's really, really important to have these embedded on our systems.

Community pharmacy workshop 2

[Introducing and using genetic information is] asking for a huge cultural shift in clinical practise to justify amassing a huge amount of information that carries so much risk that we can't even fully define yet.

GP workshop 1

I don't know that we all, I'm confident that we don't share a common trust in the idea of sort of genetic understanding, genetics, how genetics are used.

Public health 2

3.5. Infrastructure and system needs

Box 4: Summary of healthcare professional views on infrastructure and system needs

Healthcare professionals identified key changes needed within infrastructure and the healthcare system. This includes addressing **capacity gaps** and developing **clear pathways** with adequate **funding** and **clarity** of roles. Core enablers include standardised **guidelines**, sustained **funding**, collaborative **support**, and **accessible information**. Major barriers include insufficient **funding**, lack of **pathways**, and **fragmented systems**.

In this section we describe HCPs discussion during the workshops of system-level concerns and challenges associated with the introduction of genetic information, and the potential changes needed across organisations and systems to support implementation. The inclusion of these discussions reflects the prominence of

HCP concerns regarding the practicalities of implementation and system readiness. These discussions build on concerns of workload (discussed in Section 3.4.1) and lead into discussions of training and support (see Section 3.6) and equity and access (see Section 3.9). They reflect repeated anxiety about the lack of clear pathways and stretched resources within the NHS. Professionals highlighted the need for sustained funding and commissioning to enable continuity of services.

3.5.1. System readiness

HCPs situated the challenges for genomics within the wider issues associated with introducing or implementing new programmes and/or services into the NHS.

I kind of worry how to how are we going to implement all that information and how we're going to use it in primary care because (...) to be honest, it is really difficult to implement anything in the NHS.

Systems workshop 5

It's just the failing NHS keeping up with sort of forward moving, the forward moving field and I think there's a bigger picture. (...) that's where the NHS is really struggling at present.

FHCNS workshop 1

We've got a system that is currently challenged and creaking and not responding to some (...) even more basic requirements that it needs, and for me, that's the fundamental tension.

Public health 3

HCPs described a system in which readiness to implement is generally highly variable, across Trusts and in different settings. Some were enthusiastic, with others more sceptical. Several noted the need for staged, thoughtful roll out, national coordination, additional resources, and clear communication to mitigate any uncertainty and support staff.

We do need to be prepared. It's coming. It's quite clear in the 10 Year Plan. So how can we be a bit innovative about it? That's one thing I'm probably going to take away from this workshop. How can we (...) use our quite innovative forward-thinking clinicians [to] try and get something (...) around education and training.

Systems workshop 3

I wouldn't expect the scaling to all happen all at once, [it] would be quite staged.

Systems workshop 3

3.5.2. Capacity and access

HCPs shared concerns around workforce capacity and ongoing time pressures across the NHS. While workforce training and upskilling are needed (as discussed in the previous section), HCPs are already often overloaded with short appointments. This means there is not enough time for complex conversations around genetics or for incorporating additional tasks (i.e. informed consent, patient education, and follow up) into roles.

Once it starts getting down towards sort of more complex and the question of family history and genetics and implications for the future, I think that requires much more time, so I'd want it to be sort of protected [time] when we're on the ground seeing patients.

Systems workshop 3

So often this is the bit that worries me about on the ground in GP (...) 10-minute appointments [is] being able to have this conversation with far reaching implications.

Systems workshop 3

The limitations of current appointment times were also seen as a limiting factor in being able to fully inform and explain information to patients. HCPs emphasised the need for time to be able to provide information and tools to support patients with their options. Some HCPs suggested extended appointment times to allow for this, with one GP sharing an example of having longer consultation sessions.

Decisions are increasingly complex or uncertain. Then, like it's impossible to convey that in a 10-minute consultation and you need to be able to empower patients to take an informed choice but you need to be able to share the right tools with them to be able to do that and talk through with them as well.

Systems workshop 1

These questions of communication are picked up in more detail in Section 3.7.

While HCPs highlighted changes needed to enable genomics-informed care and increased levels of training/education across roles, at a system level however, there was concern around how to enable widespread upskilling on an already stretched workforce.

The challenge I feel is going to be the workforce that's in place now because everybody's already working (...) and you know, quite busy environments to try to actually get them out of that work and implement (...) the training.

Systems workshop 5

3.5.3. Pathways and guidelines

HCPs highlighted that changes are needed to current pathways and clinical practice. HCPs expressed a need for clear, structured, formalised models and pathways, including considerations around funding, staffing, and clarity of roles. There was uncertainty around who should be doing what within the system, particularly for FHCNS.

These services need to be commissioned. You can't just have CNSs (clinical nurse specialists) doing a little bit here, a little bit there within their role.

FHCNS workshop 2

HCPs discussed the uncertainty around roles, pathways, and responsibilities. At present, HCPs noted that sometimes uncertainty exists in who orders and interprets tests, who communicates results, and who manages follow-up and implications, particularly if genomics expands into primary and community care settings. Some professionals raised concerns or fears around acting outside of guidelines, raising liability and patient safety concerns.

[Guidelines need] to be in place as a safety net, and to really generate that confidence for the primary care workforce, particularly if you're thinking about, you know, the scalability of this across the across the national footprint, you know, primary care is huge (...) You do need to have that that infrastructure there in terms of, yeah, you know, guidelines that you can point to as a clinician to say, yes, I'm, I'm doing everything by the book.

Systems workshop 3

If you had your specialist teams who could do this then you've got pathways in place that will improve that patient experience.

Systems workshop 1

There was a call across workshops for unambiguous, nationally standardised guidelines and pathways to support successful implementation, noting the complexity around genetics and interpreting findings. This will improve professional ability to know what to do, reassure patients, and support equity across services and regions. Effective triage will be key to help with managing patient volume, waiting times, and referrals.

So a good running pathway and simple guidelines I think is something that I'd like.

Systems workshop 2

Like having clear guidance about who is eligible and who is not making that clear for patients in a really patient friendly [way], website or leaflet and then having clear guidance for the clinicians would be really key from from the start.

Systems workshop 3

The desire for clear, easily accessible, and regularly updated national guidelines was apparent to support testing and interpretation of results, and included suggestions of protocols, clear referral pathways, guidance on how to interpret results, and options for next steps. HCPs noted that out-of-date guidelines can minimise confidence. There were multiple references to the utility of NICE guidelines and national-level guidelines as both being trusted sources for HCPs. Current guidelines would need to be developed for genetic information, and then regularly updated in line with new or emerging evidence.

What we need is a clear national guideline and pathway.

Systems workshop 2

We need a NICE guideline of some sort is probably the way to go and the place to pack all of that information.

Systems workshop 1

I know all of our prescribers go straight to NICE for the guidelines (...) So having sort of a recognised, I suppose, is the right sort of way to kind of phrase it, recognised source of information to refer to so that they're confident they're using the right information and then they can refer back to it.

Systems workshop 3

3.5.4. Data infrastructure

HCPs highlighted the need for changes in data systems and infrastructure. They shared concerns around the availability of effective data and informatic systems to capture and integrate genetic information across care settings. The connectivity and interoperability of IT systems across NHS care are currently insufficient to support smooth and successful integration of genomics in current workflows.

[The] NHS are looking at systems and how they talk to one another (...) they don't link you with GP practices or community pharmacy always and there's a whole revamp will be needed (...) So having that transfer of information that's seamless.

Systems workshop 2

IT and data management systems were viewed as fragmented, with incompatible systems meaning results and data cannot easily be shared or accessed. One community pharmacist shared an experience where their GP practice had to withdraw from another research programme due to the IT systems being incompatible with the laboratories. As such, HCPs highlighted the need for less fragmented systems, interoperability, and dedicated infrastructure to support the implementation and use of genetic information and data.

3.5.5. Funding

Other enablers identified by HCPs were financial incentives and funding to support services and staff to be able to deliver and implement any new programme or pilot. A lack of sustainable funding is a consistent barrier for engaging in pilots and research programmes, with examples of pilot programmes stopping when funding ends and challenges for NHS organisations to be able to commit to new projects generally and related to genomics. Some HCPs expressed frustrations with previous pilot experiences and the impact on services.

Bit of frustration that it kind of was a pilot then it stopped and there's no funding and there's no national money.

Community pharmacy workshop 1

It really does worry me that even though these research studies are backed up by evidence and, you know, the conclusion is that we should be doing it whether it's ever going to happen because there's just not the money in the system to do it.

Community pharmacy workshop 1

Funding and resource concerns were also discussed in terms of the lack of physical space for consultations and the impact on communication or information sharing.

3.6. Information and support

Box 5: Summary of healthcare professional views on information and support needs

Healthcare professionals highlighted training gaps, which may **require tailored, role-specific education, and sustained support structures** to guide and build further confidence across healthcare professionals. Healthcare professionals also highlighted the importance of **resources and guidance for patient communication, psychological support, and cross-team collaboration**.

In this section, we share findings on how healthcare professionals in the workshops discussed information and support needs, including training and education, digital tools, and wider support structures.

3.6.1. Training and education needs

Across HCPs, there was a strong recognition of knowledge and training gaps in genomics and genetic information. HCPs viewed training and upskilling across the system as crucial, with suggestions that confidence in genomics will grow with exposure, structured learning, and sharing expertise across professionals.

I'm fully confident in incorporating it [genomics] today because I've spent 12 months working in it (...) my knowledge and my confidence in it has skyrocketed in the last 12 months, but that's not an opportunity that everyone has. So I can kind of understand there's a lot of reluctance, a lot of nervousness around it.

Community pharmacy workshop 2

Whilst HCPs shared an eagerness to learn and saw the value in upskilling, many described general lower levels of knowledge on genetics within current training and education. HCPs noted a lack of national guidelines or structured training programmes, which exacerbate lower levels of literacy in this area.

I suppose the only thing I've sort of picked up with talking with people in other areas is that there's no real sort of uniform training out there, which, you know, the really fast moving fields, lots of people who are taking part in it are doing it because they're excited by it, but the more I do it, the more I realise that really solid training probably would be really helpful because a lot of it is sort of self-taught.

Systems workshop 4

Many HCPs reported having little or no education in genomics or related competencies themselves, particularly those who qualified before genomics was included in formal medical training. There was broad agreement that without upskilling, many HCPs may lack the knowledge and confidence to use genomic information appropriately or be able to communicate results to patients.

I think from my perspective, I'm both apprehensive and excited about it as well. I'm apprehensive because you know, it's not only general population who lack the knowledge and information. A lot of frontline healthcare people are lacking the knowledge in genetics as well because it's so little is done outside, you know, like specialist clinics at the minute.

Systems workshop 1

From the wider workforce, there's definitely a need for improved knowledge of genomics and pharmacogenomics in general to allow that to happen, because there isn't really anything out there at the minute for pharmacy.

Community pharmacy workshop 2

The majority of nurses on the floor didn't have genomics or genetics, part of their curriculum in their previous nursing curriculum. That's reality.

FHCNS workshop 2

It's not something that is part of public health curricula.

Public health 3

HCPs noted that training should be relevant to the professional's specific clinical context and role, as different roles and specialities will require different levels of depth and focus. There may not be a 'one size fits all' approach for training and education needs. Preferred formats for education were diverse, including suggestions of e-learning, workshops, webinars, blended learning, and readily available resources. Flexibility to account for HCPs' busy clinical schedules would support upskilling.

It's very much going to be a case of making sure people actually have the time to up skill and they know where they're looking in order to help improve confidence.

Community pharmacy workshop 2

Guidance, training sessions, even if it's like online Zoom or an interactive course, it's going to have to be different (...) because otherwise it won't all be relevant.

Systems workshop 4

Further to this, HCPs suggested that genomics and genetics should be established in undergraduate and postgraduate medical, pharmacy, and nursing education (rather than an afterthought or as an extra). Meanwhile, the existing workforce will also need training and information, e.g. competency frameworks and accessible resources.

Start[ing] off with training of the workforce is key and if we are going to go with pharmacogenomics, I'm hoping in my lifetime, it will be embedded so that is part of the curriculum in university, it's the norm.

Community pharmacy workshop 1

I think the training needs to start right from your primary qualification, whether it's medical school or nursing or wherever it is, pharmacy (...) I think we need to be thinking about how we bring it in right from the get-go.

Systems workshop 3

I think the education thing is a really important thing to stress and I think it needs to start right from the primary qualification, whatever that might be, so that it becomes part of the, I was going to say part of the DNA. I don't know if that's a bit cheesy of what we of what we're learning and how we express ourselves to patients.

Systems workshop 3

In addition to general training, HCPs described a need for targeted guidance, resources and support to assist them in handling complex, sensitive genomic results, incidental findings, and having conversations about risk and results with patients (see also Section 3.7).

National templates with questionnaires, role play scenarios and what to do would be useful (...) you could have scenarios when you're explained what genetic testing is.

Systems workshop 2

It is complicated and as GPs we find it quite difficult to communicate risk scores anyway and there's a whole academic research industry on risk communication.

Systems workshop 3

Information, including results, should be simple to understand, accessible, and relevant for HCPs as well as patients. It has to be something that is, you know, you know, easy to look at (...) we don't want something that's like 6 pages long and you're looking for the wood among the trees because it's not going to be something that is used very much if we don't take into account how that information is presented.

Systems workshop 1

HCPs highlighted that current siloed, ad-hoc approaches should be replaced by coordinated, system-wide opportunities and resources. This enables training to have sustained and systemic, rather than individual, impact.

I feel sometimes when I engage with teams that have no knowledge of genomic testing and the implications (...) people are very engaged, very willing to learn. But my main worry is that we have a huge workforce and you know, in terms of how we actually deliver all this training most effectively (...) it's going to have to be a national push just because the little bits that we have, they're doing great, but my experience is that you train a person and they're very engaged and you know, run a fantastic service, but if they leave for whatever reason, then everything crumbles. So it's about sustainability.

Systems workshop 5

For training to have impact and be sustainable, timing will be key. HCPs stated that roll out of training should match clinical implementation.

Because if we did training now in primary care, when actually not much is happening, training would only be needed in five years' time. What of that training is going to remain there?

Systems workshop 4

Some recommended that information should resemble already familiar formats, for example, liver function test results.

It has to be as easy as looking up a liver function test. It has to be as easy as that really. So, we can't have lines of data we just need to be able to click through and see all information for a polygenic risk or click through information relevant to medication reviews, and also it has to be in the format of a liver function test or an X-ray report. So that's the kind of format we should be thinking about presenting genetic information as a one-page sort of thing.

Systems workshop 1

3.6.2. Digital tools for HCPs

Digital tools were discussed, with HCPs emphasising a preference for the integration of new tools and/or software into existing clinical systems and tools. Examples shared included integration of information or guidance in the NHS App and system pop-ups within EMIS and SystmOne, rather than adding something additional. HCPs wanted integration and minimal extra steps or logins, with reflections that new tools that are not embedded in existing workflows may be unused or ignored.

Anything that's not within the electronic health record, forget about it (...) you need to be able to like click on a person's health record and for that to generate whatever the polygenic risk score or whatever and

then have some information about it immediately below. I think if you have to log into different platforms or anything like that, it just won't get used, so it just needs to be as friction free as possible.

Systems workshop 1

I know we love to appify everything these days, but I don't think we need yet another app for anything. There are already more than enough apps that nobody uses, so I think resist the temptation to build yet another app. Please don't.

Systems workshop 1

Relatedly, HCPs highlighted that automated pop-ups or alerts are useful for patient safety and decision support, but there is risk of 'alert fatigue'. As such, digital tools need to find a balance between too many interruptions or persistent updates with providing the critical information needed to support decision making.

I mean SystemOne does have alerts when you're about to prescribe something. The only thing is it does have an awful lot of alerts. So, it's getting rid of how you combat prescriber alert fatigue.

Systems workshop 2

In line with the discussion of information needs above, HCPs noted that digital tools should be usable and accessible. Too much complexity or the requirement for multiple clicks or logins makes tools unappealing for HCPs and patients. HCPs highlighted that decision-support systems that include and pre-process information (e.g. risk scores, pharmacogenomics) and generate clear, actionable recommendations are desired. Many stressed that it is crucial for these tools to link back to guidelines and that there was a preference for automated updates as evidence grows and changes.

You really need that system in place to say actually this is what this means and you should do this or you should consider this because there's just a lot of information and I'm sure this information will only continue to grow as we expand this further.

Systems workshop 3

The digital software that's going to be used to enable that clinical decision making is so important that it is something that is that is live and that can continue to be updated, continuously be updated (...) that entire process cannot be reliant on (...) human effort.

Systems workshop 3

Artificial intelligence (AI)-powered tools were also mentioned, with some HCPs noting the potential these could have for supporting complex data interpretation and decision-support. These reflections were coupled with concerns around a lack of transparency and black box effect, a requirement for ongoing training, and risks of errors in interpretation. HCPs stated the need for strong guardrails in place to reduce bias and inaccuracies.

There's the risk of the black box effect and lack of transparency, how decisions have, you know, how the outputs are generated, the risk of bias if it's been trained on a specific type of data set that considers certain parts of the population and so on.

GP workshop 2

If you're going to bring AI into the equation, you know that is my concern is that AI is not 100%. It's like a baby. You need to train it.

Systems workshop 2

As long as the AI tool is transparent and not biased and all the things and trustworthy and so on, great.

GP workshop 2

HCPs highlighted the importance of standardised digital tools across the system to enable them to be effective. Interoperability was noted as important for accessing information and enabling interactions across the healthcare system, with current practice viewed as fragmented and disjointed with systems not talking to one another.

3.6.3. Support structures

HCPs shared a strong need for access to expert support, particularly as some roles are generalist by nature (for example GPs) and therefore not specially trained in genomics. Access to expert support was suggested in a variety of options, e.g. in-person and digitally. This support could include the availability of networks, meetings, mentorship, workshops, and knowing who to speak to for advice. Some HCPs reflected on the benefit of having multidisciplinary teams where professionals can discuss with others and work together. Examples were shared where some HCPs had regular meetings with other colleagues to discuss patient care, as needed, and provide support to one another. This was both within roles and with other professionals.

It's the clarity of who to call if we need some input in interpreting some of the results.

Systems workshop 2

Support structure suggestions included clinical or local genomics champions, and peer learning or sharing opportunities. This would enable sharing of best practice and knowledge, alongside supporting less experienced staff. Communities of practice could then be developed between and across services. Some HCPs noted that they currently delivered genomics-related training or supported others within their teams and services, supporting their workforces in developing literacy and knowledge in this area.

It would be nice to nominate like a champion who can maybe regularly attend workshops like this where people can share their practise, their resources, and then they could feedback to the rest of the team.

Systems workshop 2

Any new doctors, any new surgeons that come to work in the team will come and spend an afternoon in a clinic with me (...) it also is quite good because (...) I am the only family history nurse and it's quite isolating.

Systems workshop 2

Some clinicians like having a champion or an expert in a field to be able to refer to or they would know maybe more than they would, and they can teach them like a peer.

Systems workshop 2

Having collaborative networks and support in place can enable successful implementation. These networks enable access to expert advice and peer support to build confidence, knowledge, and solve challenges if and when they arise. As participants in one FHCNS workshop reflected on within their own current practice and the benefit of support from colleagues and other teams:

We've got good working relationships, so that makes us more confident that if we're not sure what to do, we've got somewhere we can go.

FHCNS workshop 2

3.7. Impact on patients

Box 6. Summary of healthcare professional views on patient impact and support needs

Healthcare professionals highlighted that clear, **personalised explanations, delivered in accessible formats and supported by sufficient time, counselling and follow-up**, can support patients with understanding and interpreting genetic findings. Patients will need **adequate support**, including resources which are offered in multiple languages and formats.

In this section, we discuss the potential impacts on patients shared by HCPs. This includes considerations for communication, health literacy, and support needs.

3.7.1. The value of personalised communication

HCPs discussed patient communication and understanding, with some reflecting that if genomics and genetic information can help personalise and target care, patients are more likely to engage in healthcare. If medical appointments and interactions feel more relevant and individualised, patients may engage more and have improved satisfaction with the healthcare system.

I think if an individual, if they know that something's personalised to them [they are] perhaps more likely to use it correctly.

Community pharmacy workshop 2

I think being able to back [a prescription] up with data and testing would probably, well, I hope would sort of encourage them to be more not trusting, but willing to sort of use it. (...) I think maybe having that data to back it up and say to them, well, this is for you, this is the best, you know, what we think

is going to work best may sort of get that engagement a bit more.

Community pharmacy workshop 2

Further, if a treatment recommendation is accompanied with a lower chance of side effects or evidence that suggests something will work well for that individual, there may also be improved health outcomes. Communications that highlight an individual's context could improve experiences for patients and empower them to be involved in decision-making. HCPs noted that many patients now seek an active role in their health, for example, seeking additional information and/or taking action.

I think we're now in a world where patients want that involvement in the care (...) patients actively want to take, you know, take the opportunity to have a role in their care and I think, you know, genetic testing and further testing it sort of encourages that patients want to know, they want to know what their options are, what treatments are available. And so, I think it'll have a really big impact.

Practice nurse workshop 1

HCPs pointed out that genetic information can be highly complex, which can be challenging to communicate. The nuanced and shared familial nature of genomics was seen as an added layer over already complex healthcare, requiring a thoughtful approach for implementation in both clinical use and patient communication.

Just thinking about our role as kind of family physicians, you know, we look after everyone's like families as a whole and we probably know, you know, who's related to who and stuff depending on the size of our practice. So you know, if a patient of ours had a genetic test (...) but we're also looking after, you know, their mum, their brother, who maybe hasn't had those tests or the result of the test for the initial patient

has an implication for these people, you know, to what extent is our role in proactively approaching them about these discussions, but also, you know, if we know that the initial patient is more sensitive to a medication, can we take it upon ourselves to apply that information when managing their relative?

GP workshop 2

3.7.2. The personal impact of communication

The complexity of genomic information is compounded by the implications of results for individual patients and for their family members. Personalised risk communication could cause distress or difficult conversations around inherited risks. Genetics and risk could be overwhelming for patients, particularly those who receive a positive or uncertain result or who have lower health literacy. HCPs recommended that time, space, and support would be essential for patients when receiving findings or discussing genomics. This includes time for discussions with HCPs, genetic counselling, and access to resources or guidance.

For some patients, it might frighten them knowing they might [in] the future be more likely to have a heart attack or whatever.

Systems workshop 2

These are very complex concepts. There are also concepts that are being introduced to people that are cancer patients and that are already being very overwhelmed with information (...) So it's a lot for people to take in and to get their heads round and my experience [is that it's] possible people don't always grasp the implications of a positive result (...) you're telling people things that possibly doesn't just affect them, but effects, you know, a whole host of the wider family.

FHCNS workshop 2

Professionals described uncertainty both in terms of what results mean for a patient, and in how to communicate uncertainties effectively without creating unnecessary anxiety or false reassurance.

Many people just don't know how to break the news or how to, you know what that will mean to the person or to the to the family.

FHCNS workshop 1

HCPs suggested a need for pathways that ensure effective counselling, and clear communication of benefits, risks, and incidental findings. Results could cause anxiety for patients, alongside confusion and/or distress, particularly if findings are unfamiliar or uncertain. The model described, particularly by FHCNS participants, is often that of pre-/post- test genetic counselling, with one example shared of a service in which a clinical psychologist supports patients throughout their journey.

I think genetic testing is a very sensitive process and I think sometimes that gets lost somewhere along the way (...) I think [patients] need really good counselling for that because they find that very overwhelming.

FHCNS workshop 2

Thinking about what patients really need, there are two stages I guess (...) it's what they need pre-test and what they need post-test. And obviously as others have said pre-test, I think you know how counselling, counselling is handled is very, very important and obviously has to be tailored to their understanding.

Systems workshop 3

If we have any patients who are struggling if they've got a cancer diagnosis and we're going on to offer genetic testing or risk reducing surgery, the pathway [is] that they see the clinical psychologist before any surgeries undertaking, especially if it's risk reducing just to make sure that that

they're making the decision based on obviously informed, an informed decision and not a knee jerk reaction and that they're hopefully not going to regret that decision later on down the line.

Systems workshop 3

More broadly, HCPs discussed the importance of allowing time for discussions with patients around testing and findings, alongside counselling support and follow-ups. This applies to both in-depth conversations to discuss informed consent, support throughout decision making particularly where results are complex and/or affect families. Examples of this were shared in a family history context, where some FHCNS described the longer appointment times in place to allow time for these discussions.

We have an hour appointment for when we see patients and when we give results as well. And I think that that hour is needed, not every patient needs it, but again, I think it's important that you've got the time. You've got the counselling skills, you've got a good understanding of genomics and the associated cancers, and you've got a good pathway in place that you can refer patients on to discuss the results further and how you're going to manage that future risk.

FHCNS workshop 2

3.7.3. Health literacy

Health literacy was raised by HCPs as a key potential barrier to effective communication of genetic information and results. Language and literacy present barriers to understanding and interpretation, with notes that some health terms do not have direct translations in all languages. HCPs recommended information being provided in multiple formats and languages, using visuals and simple language, rather than jargon.

We identified the need for translated patient information, acknowledging the fact that certain terms we use in medicine might not have an equivalent term in that patient's native language.

Systems workshop 3

I think there was a study somewhere that looked at how many bits of information a patient was given in a clinic, an outpatient clinic appointment, and how many they remembered. And the average was about seven pieces of information and patients generally remember the magic number of three (...) that information needs to be accessible so that if they're looking at it at 3:00 in the morning because they can't sleep and are worried, they can understand it (...) we just need to make sure that we don't create more problems.

Systems workshop 3

HCPs also reflected on concerns around public perceptions of genomics, which could further complicate conversations and in some cases reduce engagement and trust with the healthcare system. They highlighted that due to the complexity of genetics and genomics, patients may have misconceptions or misinformation regarding the meaning of findings or of healthcare more generally.

We're going to have to train the patients as well. So, the better we train, the better we can deliver that information to the patient [otherwise it's] all a vicious cycle.

Systems workshop 5

I'm coming from the lack of education angle and that the patient becomes very distressed at the misinformation of genetics and testing and the impact.

Systems workshop 1

One potential risk of lower health literacy raised by HCPs was that patients may not fully grasp the implications of findings for either themselves or their families. For example, some HCPs shared examples of direct-to-

consumer tests being brought to them and confusion from patients around what these tests can, and cannot, provide information on. Thorough conversations to support patients with informed consent and understanding were seen as key to supporting patients and communicating.

It's just about real misconceptions and very informed consent when you're doing this kind of work and testing.

Systems workshop 4

So you know, being able to actually give them that information and explaining it and if they have got a gene and making sure they do understand what it means for family members (...) it's really supporting them with that information.

FHCNS workshop 1

Patients need information and then how do you deliver that information and then cascading it to their family members of the results on the outcomes that it's really kind of [a can of] worms that you're opening up when you're doing genetic testing and there's so much information that needs to be cascaded to the family that it can have a huge impact cycle.

Systems workshop 1

Conversely some HCPs, particularly those working in public health, reflected concerns that genomic information and results be seen as more important than other health information and risk factors. For example, if emphasis is placed on genetic risk, could this then reduce the importance or utility of behavioural and lifestyle factors. Introducing genetic information into routine practice may shift focus and place too much emphasis on individual factors, rather than broader factors (for example, lifestyle and environment).

If they have, if their lifestyle and cholesterol give them kind of a certain level of risk and then their genetic profile says that they're less well, it reduces their risk. Does that inadvertently signal to the patient that the lifestyle parts don't matter?

Public health 1

[Genetic information needs to be introduced and used] not at the expense, however, or replacing some of those issues around the social determinants of health, like housing and water quality and quality of people's work and things which are, you know, having a huge impact on people today and we can do something about it.

Public health 3

This concern emphasises that communication about genetic information is not simply a case of ensuring that risk is effectively conveyed, but that the information is contextualised. To address this, some HCPs suggested national or local campaigns to address myths and patient questions.

I was thinking public awareness is going to be really important as well, and there'll be some campaigns to explain that this is happening what it is and (...) be sure, because some people will be nervous

Systems workshop 4

It could be that we need maybe national campaigns about, you know, our attitudes as a society about genetic testing and how this, you know, we maybe should change our mind first because sometimes people see it as (...) a curse, some people see it as a stigma, some people feel guilty.

Systems workshop 5

3.7.4. Support needs and digital tools for patients

HCPs discussed needs for support to enable effective communication of complex information and support health literacy. This includes clear explanations before, during, and after genetic testing and the feedback of results. These materials should be easy to access and read, suited to the needs of patients, and available in multiple formats, using a combination of digital and offline methods to ensure diverse patient needs are met e.g. for those facing digital exclusion. Support would also be beneficial for navigating services, with HCPs highlighting the need for clear pathways and signposting to support patients.

One important pre-step there will be explaining to the patients that that test needs to be done, explaining what the (...) test means, because when they hear about or hear about genomics or genetics or testing, they can imagine anything futuristic.

Community pharmacy workshop 2

[The] availability of the information should be available in a lay language, lay people's language and also with some illustrations, leaflets and things that (...) makes it more understandable, more accessible to patients that help us in the, you know, the healthcare professionals to have that discussion with the patient and the patient chooses the right thing for them.

Systems workshop 1

I think sometimes simple resources like posters in a community pharmacy when patients are waiting for the prescriptions to be dispensed or like waiting a room in a surgery waiting room videos, they are quite powerful information.

Systems workshop 2

We have to put things in our media at a practice level, and we'll have to use leaflets because obviously that people that prefer paper-based formats rather than digital.

Systems workshop 3

The design of materials in multiple languages and accessible formats would enable the Adult Population Genomics Research Study (known as "the research study") to meet the needs of a range of patients and facilitate equitable access. Additional suggestions included printed, pictorial, easy-read, and video resources. Similarly, all communication needs to be tailored to patient needs and include touchpoints as required.

We need all those resources for just to be mindful around people who are digitally excluded, for example, and how we communicate to that cohort of patients as well.

Systems workshop 3

Some HCPs highlighted the potential role of digital tools or resources that patients can access. These tools and information sources should be reputable and centralised, for example a website or app that can give up-to-date and accurate information. One example shared was integration in the NHS App.

Maybe like a really good online resource that's probably NHS funded and secure, because obviously if you start Googling, you can go anywhere with this information, which is always dangerous. (...) so maybe having all the different types of genetic testing you know, and what way they're used on one site that people can be signposted to, that's a really safe site to use, which will take a lot of work to create, but it would at least all be maybe in one place for the future people to be directed to.

Systems workshop 4

3.8. Access and equity

Box 7: Summary of healthcare professional views on access and equity

Healthcare professionals reflected that both **genomic data** and **access to services are often skewed** to particular groups and there are risks of increasing health inequities. Healthcare professionals suggested ensuring **diverse recruitment, tailored communication, flexible support roles, and standardised approaches** to ensure equitable benefits for all patients.

Equity of access to healthcare and genomic medicine were identified as key themes through the research, particularly around systemic constraints on who will benefit from genomic medicine and how much confidence patients (and the wider public) will have in this information.

HCPs raised the importance of a fair approach, questioning whether certain populations, particularly those from ethnic minorities or groups with historical reasons for distrust in healthcare, might be excluded from a future programme. Discussions of the use of genetic information emphasised the potential for genomics to enable the more efficient and effective targeting of resources to those who need it, and thus the potential to contribute to more equitable care.

[It] is about saving resources and spending the time and the resources on the patients and the person that needs them the most. And if this is going to be a tool that will help us manage the amount of patients that we need to scan or or do tests or whatever, I think that's going to be a huge step ahead.

Systems workshop 5

I think the opportunity for risk prediction and stratification of resources to the patients who need it most is (...) very attractive.

Systems workshop 2

So personalising will mean that we are targeting the (...) individuals that actually really, really need that particular, you know, management strategy, whatever that is. So really exciting for me.

Systems workshop 5

3.8.1. Access barriers

HCP discussions highlighted access barriers associated with genomics and access to healthcare more broadly. HCPs noted that access to healthcare, generally and genomic-specific, varied across their patient populations. HCPs emphasised that the pressures on the NHS are not even, with variation in access and the availability of services across areas. There were concerns around a postcode lottery for access, with big variations seen between professionals and even within roles (for example different experiences between different FHCNS and what their role entails).

It comes down to funding and that's the bit that we really also need to focus on because not everywhere is equally funded and there's still lots of disparaging services

FHCNS workshop 2

If it's a complex area, there might be inequities, just depending on who your GP is, how well informed and trained they are as well.

GP workshop 2

We tend to all think that the biggest issue is misinformation, but we [public health] would counter that with there are many people who would like to take part in public health services but are just not given the opportunity or the access or the time needed to take part.

Public health 3

Access can be hindered by deprivation, language barriers, low health literacy, and digital exclusion. Some professionals shared that patients sometimes come into practice with private testing results, whereas others are likely unaware of genomic services or the available resources.

I haven't seen patients coming in with a privately obtained genetics test of theirs. I work in a pretty deprived community (...) so maybe they (...) spend their money, what money they have on other things.

GP workshop 2

Lots of my patients, they don't have access to the Internet because they can't afford a phone. They can't afford the Internet or they're over 80 and they don't have one.

Systems workshop 3

I suppose some of the unintended consequences might be around generating more inequities, you know, because it will be the sort of educated cohort of patients who come and ask for the genetic test.

GP workshop 2

HCPs also raised the risk of systemic negative impacts on patients through amplifying inequities, with reflections that the already-engaged patients will be the ones who benefit the most and the less-engaged are left further behind. Local inconsistencies between and within local areas can lead to further inequalities and a postcode lottery. HCPs suggested a standardised approach to who can access genomics and to target interventions to those least likely to benefit otherwise. Monitoring of where uptake is low or where there are gaps was also recommended when designing and implementing a programme or new service. This also applied at the national level, with suggestions of standardising across England and creating centralised resources nationwide.

So the people who utilise this information are the people for whom is probably going to make less of an impact and they're already well engaged in health services and the ones who won't and the ones who arguably need it more are the ones who are, you know, struggling to engage in health services as they are.

Systems workshop 2

You're only down the road and it just feels like things change so massively, just crossing a border as to what is available to people.

Practice nurse workshop 2

If you decide to target a specific group, you know, there's something around, for example, ethnicities I mentioned, and it could backfire in terms of unintended consequences as to, you know, why this group and why and what are the consequences, what, what, how the data is going to be stored, all that kind of stuff.

GP workshop 2

It would probably land well for the educated, informed, articulate population. It would probably have, where it would have less benefit were we to organise it for people who typically don't access services.

Public health 3

As services are currently designed and delivered, HCPs reported that some groups are typically more disengaged due to history and/or practical barriers.

At the end of the day, I end up just explaining it all myself because that is the best way for me to get that information over, which is why I have 20-minute appointments and not ten and we have that across the board in my GP practice because that's the only way that we can deal with our patients effectively.

Systems workshop 3

We've run a specifically designed service to get Turkish, Kurdish, Afro Caribbean patients to basically have their health checks because we know in our local area that these are patients don't really engage with the healthcare system because they're kind of sceptical of how data is stored and who knows about their health problems and things like that.

Systems workshop 1

Recommendations also included engaging with a range of different HCPs, such as community pharmacists and care navigators, for education and outreach, and to provide face-to-face options.

So I think that interface should be filled by other people in primary care. We call them care navigators now, (...) I think we need to enhance that role as well so that you know that care navigate or interface between general population and and that person has the role of care navigation, they equally have the role of patient education as well.

Systems workshop 1

Another proposal was for longer, flexible appointments where feasible and providing professional support to help patients navigate and engage in the healthcare system. As described in previously, HCPs, particularly GPs, repeatedly raised concerns about time and capacity constraints. They noted that not only would standard appointments be too short to include discussions of genomics and genetic information, but that this would be particularly the case for patients with complex needs or communication barriers.

3.8.2. Genomic data equity

One significant aspect of the potential of genomics to contribute to inequity, however, relates not to the nature of the health system but to that of genomics itself. HCPs were aware of, and discussed, the limitations of representation and validity in current genomic data, particularly with reference to

polygenic risk indices and pharmacogenomic profiles. HCPs recognised for example, that pharmacogenomic profiles may differ by ancestral group.

I think that's potentially really useful because you know when people take any medication, they're concerned about side effects and we know that some drugs have differing effects in in some population groups versus others.

Public health 1

However, as the populations included in genomic datasets are biased towards people of European ancestry, derived polygenic risk scores and pharmacogenomic findings may not be applicable or accurate for everyone. Many HCPs reflected the overrepresentation of European ancestry data and the implications for accuracy and clinical utility across diverse populations, with risks of exacerbating existing inequalities.

Most of medical research is presumed to have been done on Caucasians, therefore isn't right for people from other backgrounds.

Public health 2

Our understanding and interpretation of a lot of the genetic information isn't equitable because a lot of the data, the evidence that's feeding that information is already skewed towards, you know, European ancestral population. So again, there is a there's a question there around clinical usefulness and whether that would be equitable.

Systems workshop 3

So if we are going to provide genetic information [it] needs to be based on data that's as varied as the population that we're giving it to essentially. Otherwise, I think there is a risk of perpetuating and exacerbating health inequalities or providing inaccurate information to people.

Public health 1

the data that's been collected is enriched with kind of Western European heritage, and it's underrepresented certain heritage groups. So that just from a kind of analytical point of view means you're going to get better information for certain groups of people than other groups.

Systems workshop 2

Looking forward, recruitment into a study should consider approaches to recruiting from underrepresented groups to improve representation and data validity, and to consider how to communicate risk information that may differ in its predictive value between ancestry groups. HCPs recommended that recruitment is diverse and that inclusivity is built into research design from the beginning. Further, evidence and guidance on interpreting genetic information needs to be adjusted and updated as the data broadens.

So I think health inequalities is a really a really kind of big bit that we don't want to miss. So if we are going to do a big genetic study, we want to kind of ensure that we have representation from all different kinds of backgrounds, from where people come from, different ancestries, etcetera, so that we can trust the information that comes out at the end of it.

Systems workshop 1

3.9. Consent and data access

Box 8. Summary of healthcare professional views on consent and data access

Healthcare professionals had mixed views on data access, but there was emphasis that genomic data should be **accessible to those directly involved in patient care and on a need-to-know basis**, guided by established principles. Patients should also have **informed consent over access and sharing**.

In this section, we present findings on how healthcare professionals in the workshops viewed topics of consent and data access, including storage and security.

3.9.1. Data access

HCPs shared a range of views on who should have access to genomic information and under what circumstances. There was a repeated emphasis that only HCPs directly involved in a patient's care (e.g. their GP, dispensing pharmacist) should access genetic data, and only when it is relevant to treatment or medication decisions. Other HCPs suggested that access should be a 'need-to-know' basis, with staff only accessing and seeing what is required for their clinical decision making. There are also existing data governance principles used within the NHS, and some HCPs suggested that this approach should also be taken for genomic information and data.

Yeah, I think only healthcare professionals who are involved with that patient's care should have access to that information because therefore it may be relevant for treatment or medication, etcetera. I don't think anyone else should have access to it unless they've got direct contact with that patient for clinical reasons.

Systems workshop 3

I have mixed feelings about this. I feel that only on a need to know basis the information should be available. I feel that it should also be somebody who can action an outcome.

Systems workshop 5

HCPs also highlighted that informed consent to data access and sharing is essential and that individual patients should have a right to choose and control who has access or can share their information with others, e.g. for research or with family members. HCPs highlighted the need for clear options, robust explanations, and consideration for individual

preferences. Some also reflected on the far-reaching implications of genetic results which can impact family members, and there should be an option to obtain consent to inform a family member where relevant or appropriate.

I think we should be guided by what patients want and that doesn't necessarily mean that, you know, we can sort of assume what they'd be comfortable with. (...) So I think possibly thinking about how there could be maybe even like tiered access that could then again take into account what patients are particularly comfortable with so that we don't create a system where you're only benefiting from some of the clinical utility in terms of genome informed healthcare if you're willing to hand over X amount of your data.

Systems workshop 3

I think that's probably one of the biggest things in terms of the roll out of all of this. I think the patient should be the owner of their own data.

Systems workshop 3

Many HCPs felt that patients should have control and access to their results, for example via the NHS App, but with support and guidance in place to avoid potential distress or confusion around what findings mean. Access to data can empower patients, but there can be risks in providing this access if information is not complemented by guidance for patients, as discussed in Section 3.7.

I've noticed quite a big shift in the past, probably couple of years since [patient] results can be seen on their NHS app that a lot of patients are taking more ownership and they've seen the results before we even ring them and (...) they were feeling a bit more empowered.

Practice nurse workshop 1

Third party access and insurers were also discussed by HCPs, with views that this could be a concern for patients. This raised ethical dilemmas around who owns the data and the potential for genetic information to impact on insurability, which needs to be considered when designing a programme.

there's major ethical implications and the consent procedure has to be really robust.

Systems workshop 3

3.9.2. Data storage and security

Concerns were shared by HCPs around data storage and security, noting wide distrust around storage and security amongst some patients. Genomic data can be viewed as highly sensitive, which raised concerns over secure storage, who has access, and the potential misuse and discrimination, particularly with genomic information where there is currently less understanding or knowledge. HCPs noted that this is a worry for both clinicians and patients alike, emphasising the need for robust procedures and safeguards.

I just wanted to say with the genetic data, I think there could be some worries because you know once you've got it, it doesn't change. So if someone gets hold of that, what are they going to do with it? I think there might be some, you know, you have to just make sure it's really secure.

Community pharmacy workshop 1

We worry that there might be a lot of information that is generated that we don't at the moment have any use for or we don't even know the significance of but could potentially be unhelpful information, or information that might open the door to some form of discrimination in the future.

Systems workshop 1

I think the practitioners themselves should have a deep understanding in terms of what you know what in terms of you know the data access is going to be like in the privacy issues around that as well. Because if we aren't able to answer those questions then the patients won't be able to put their trust in us and you know, probably have a look at misinformation online and further perpetuates that sort of underlying mistrust that they possibly have.

Systems workshop 3

Overall, there may not be a one-size-fits-all approach to access, but rather one that is guided by the patient's preferences and clinical decision-making needs.

4. Discussion and conclusions

4.1. Discussion

Our findings show that HCPs are broadly optimistic about the introduction and use of genomic information in healthcare, particularly its potential to enable more personalised, proactive care with improved risk prediction and prescribing decisions. However, enthusiasm is tempered by concerns. These concerns include risks of negative impact on patients, exacerbating inequalities, and around implementation. HCP concerns included risks associated with increased complexity and uncertainty, knowledge and training gaps, and issues of equity and trust (particularly for underrepresented groups).

Key enablers identified include comprehensive, tailored training, standardised guidance, clear pathways, funding, collaboration and support, and accessible information systems. Barriers and challenges identified included workforce pressures, fragmented infrastructure, and risks related to equity and inequalities. HCPs highlighted the need for up-to-date national guidelines, integration into existing systems, and practical resources (e.g. for patient communication).

The findings emphasise the extent to which the hopes and concerns of healthcare professionals working outside traditional clinical genetics contexts echo discussions around genomics in policy and genetic medicine – including concerns about impact on patients and the delivery constraints associated with the current NHS context. They also emphasise, however, the importance of recognising and working with the NHS context in implementation, as something that rests on existing skills, relationships, infrastructure, and distributions of resources. This has potential benefits, for example where adult population genomics can build on skills and knowledge in public health and primary care related to risk communication, be incorporated into

functioning digital platforms, and become routine. However, it also comes with risks, not least in terms of reproducing existing inequalities in access or data and evidence or adding stress to already overloaded individuals and systems.

Overall, the engagement findings build on the commissioned Genomics England literature review (Fava Health 2025) and the current evidence base, as discussed further in the following sub-headings. Our report provides insight into the views of healthcare professionals across England who would potentially be impacted by using genetic information in practice and through the adult population genomics programme. In doing so, it expands the limited existing work undertaken in the UK, which has previously been either quantitative (Evans et al. 2020), or focused on only one domain, such as cancer screening (Ayoub et al. 2023) or pharmacogenomics (Rafi et al. 2020). Further, whereas existing work in the UK has primarily focused on general practitioners, this study also adds the perspective of groups, such as practice nurses, who have not previously been consulted in detail on the implementation of genomics.

The findings of the report can be used to inform Genomics England's design of the research programme and provide direct recommendations for doing so. However, our work, in combination with recent evidence reviews (Dunlop et al. 2025; Fava Health 2025), suggests that there may be persistent challenges in the introduction and use of genomics into population healthcare that require wider systemic attention.

4.1.1. Optimism about clinical value, with conditions

Overall optimism about the potential of genomic information to enable more personalised and proactive healthcare is a consistent finding across our research and the established literature. General practitioners and pharmacists, for example, have been shown to prefer pharmacogenomic testing over standard models of prescribing (McDermott et al. 2024; Mai et al. 2024). There were also mentions of improved prediction, more targeted screening, and improved prescribing decisions as areas of key value. These views reflect prior findings that clinicians do see value in genomics for healthcare, including prevention, management, and prescribing.

However, this support is conditional. HCP views on genomics are variable, and contingent on robust evidence, actionable results, and clear benefits. Although genomic information was seen as mostly acceptable and promising, some HCPs questioned its clinical utility, for example in contexts where risk prediction is not yet fully understood and evidence is still evolving (e.g. polygenic risk scores). Concerns around uncertainty and unintended consequences (e.g. patient anxiety, change in behavioural or lifestyle factors following results) mirrored findings identified in the review.

Concerns were more pronounced around some areas than others, for example, there was a widely held view that there is more evidence for pharmacogenomics compared to polygenic risk scores. As such, HCP views on clinical value may vary depending on the use and application in practice. Consideration around how genetic information is used in practice and under what circumstances, will need to include reflection on the current evidence and where necessary seek to address any evidence gaps.

4.1.2. Variation in familiarity and professional role boundaries

Both our findings and the literature highlight variations in familiarity with, and perceived relevance of, genomics across HCPs (Ayoub et al. 2023, Lapointe et al. 2022, Kenneson et al. 2025). In the case of genomics, and in the implementation of innovation into primary care in general, time, workload and resourcing are major barriers (Dunlop et al. 2025). Although some professionals use genomics routinely (e.g. FHCNS), others reported more limited exposure and knowledge. This resulted in mixed views and expectations regarding impact on individual roles and workloads.

These findings reinforce evidence that some roles face tension between the breadth of their responsibilities and the perceived depth of knowledge required to use genomic information appropriately. In line with previous work, some HCPs position their roles focused on referral or initial patient contact, rather than detailed interpretation. Others expressed interest in more detailed engagement, including co-management with specialists, but needing the structured support to do so.

This highlights that the HCP perspective is not singular. Professional identity, training background, and context meaningfully shape how genomics is understood, used, and operationalised. Implementation therefore will need to account for this variation.

Our findings in particular highlight the differing needs and perspectives across roles, including differences in perceived outcomes and impact. FHCNS noted that increased use of genetic information would add onto their already high workload but others, particularly community pharmacists, shared that not much would change in their day-to-day. Through workshops, different roles highlighted their different needs. For example, some GPs noted the nature of their job is to be more general and as such more baseline training may be needed. These findings show the

difference between roles and highlight that programme design and set-up needs to account for different starting points across HCPs.

4.1.3. Training as necessary but not sufficient

The need for comprehensive, tailored training and resources was a consistent theme across both the literature and our findings. HCPs emphasised the inclusion of genomics from first or primary medical training, ongoing professional development, and practical training not only the basics of genetics but on communication, ethics and informed consent, and decision-making. The literature also suggests multi-professional learning environments and blended delivery models (e.g. online and in-person formats) are valued (Lapointe et al. 2022; Kenneson et al. 2025, Nightingale et al. 2025). Our findings also highlighted this preference for flexible and accessible options.

However, access to training and education does not automatically result or translate into uptake or adoption of genomics in population healthcare (Dunlop et al. 2025). Workforce pressures and competing priorities were some of the many barriers shared. This is reflected in the literature, which highlights concerns related to institutional and service level constraints which may undermine new programmes (Nightingale et al. 2025, Marlowe et al. 2025). Without changes or actions to address existing barriers and pressures, education alone may not be enough.

The findings in this report add to this evidence by drawing attention to the different needs across different HCP groups. GPs, for example, may need specific training in risk communication and patient interactions on genomics, whereas for public health there may be a need for more general education and increased familiarity of genomics. HCPs also have different roles at various stages of a patient's journey. For example, a GP may undertake the initial consultation, and

then a pharmacist may be involved in the following prescribing. As such, training will need to fit in with each HCP role and where they fall within the pathway – reflecting Evans et al.'s description of 'just in time' education (Evans et al. 2020). Notably, there appears to be a general need for upskilling across professionals, with most survey respondents indicating that they would need 'some', 'quite a lot', or 'a lot' of additional support. But, this should, in part, also meet more specific needs according to role boundaries and existing expertise.

4.1.4. System integration and infrastructure

HCPs emphasised the need for clear national guidance, standardised pathways, funding, and integration into existing systems. These findings closely reflect insights from the existing literature around the importance of service design (McDermott et al. 2024, Tommel et al. 2023). Moreover, these findings appear to be persistent. As Dunlop et al. (2025) describe, concerns around the lack of referral guidelines have persisted over more than a decade, despite programmes and efforts to improve uptake of genomics in primary care. As they suggest, this requires concerted attention to systemic issues beyond education alone, addressing the challenges facing time-and-resource poor clinicians.

In this engagement work, systemic issues included infrastructure, complexity, and the need to work with existing systems. HCPs working in primary care, pharmacy, and secondary care raised concerns around the fragmented data infrastructure. While similar considerations have been highlighted in the 'mainstreaming' of genomic medicine (Friedrich et al. 2024) this is a particular concern in the case of primary care and community pharmacy, where multiple competing (and potentially incompatible) data systems are in operation. There is a risk associated with adding complexity into an already pressured system, and participants emphasised that genomics should be viewed

as something that needs to be meaningfully integrated into existing clinical workflows and systems, emphasising incremental gains and easy wins. Where pathways are uncertain, responsibilities are ambiguous, or the benefits unclear, HCPs anticipated risks and added pressures.

4.1.5. Equity and widening inequalities

Our findings placed some emphasis on equity and trust. These findings aligned with concerns in the literature about the interplay between genetic risk and the social determinants of health (Rosso et al. 2020). Barriers in access to genomics are also compounded in populations that are already excluded from, and underserved by, healthcare, including rural, migrant, non-English speaking, or socioeconomically disadvantaged populations (Dunlop et al. 2025). A further layer of complication is uneven public engagement with, and attitudes towards, genetics and genomics. Women, older people, those with lower incomes, who do not have tertiary education, and who self-identify as belonging to a minority ethnic group are less likely to be willing to participate in genomic studies (Middleton et al. 2023). General distrust of healthcare, and genomics, may further inequities to healthcare with certain groups choosing not to engage in programmes or the wider healthcare system (Atutornu et al. 2022).

In this work, HCPs highlighted barriers to equitable access to healthcare, and expressed concern that genomics could exacerbate existing health inequalities, particularly since underrepresented populations are not adequately reflected in genomic datasets or if access to testing and follow up care is uneven. There were also concerns around a postcode lottery. Active efforts should be made to both ensure an equitable approach to design and recruitment, and to also seek to build trust and address concerns across communities (Atutornu et al. 2022; Lemke et al. 2022).

4.2. Implications for the Adult Population Genomics research study

The HCP engagement findings allow us to draw out key recommendations and learnings for Genomics England, and the design of the research study. Recommendations targeted at further engagement with HCPs, reflecting on the experience of this project, were provided earlier in this report (see Section 2.7).

4.2.1. Recommendations and learnings for the research programme design

- Genomics England needs to continue relationship building across the system, to maintain trust and build engagement. This includes working with HCPs, patients, and other stakeholders and organisations across the system, and being responsive to concerns when they are raised.
- The programme should be embedded within existing NHS structures, pathways, systems, and infrastructure rather than alongside them. This will help ensure feasibility, practicability, and scalability of the programme.
- Equity needs to be embedded from the outset of the programme. This should include ensuring diverse and representative recruitment of participants, monitoring uptake of genomics within adult population healthcare and outcomes, access opportunities, and continued engagement with underrepresented communities.
- Patient and professional communication needs to be accessible and clear to improve understanding and utility of genetic information. This could include dedicated communication programmes, guidance shared with patients and HCPs, and materials in different formats.

- Within the programme, there should be an acknowledgement of where the evidence gaps are and efforts to actively address them. This will help address and support HCPs and patients to engage with potential uncertainty around current evidence and strengthen rigour and stakeholder trust.
- Governance and data security need to be carefully considered to address concerns around data privacy and access. These should align with NHS, national, and international standards and incorporate the work that Genomics England has already done in this area. Governance and data security measures within the programme would need to be clearly communicated to HCPs and patients to help build and maintain trust.
- HCPs need relevant and tailored guidance and training. Training should be role-specific, practical, delivered at the appropriate depth, and embedded within professional development.
- Clinical decision support tools should be developed and implemented to support HCPs. This would help to combat clinical cognitive burden through adding more information, and instead have information embedded in clinical systems and actionable.
- Collaboration and multi-disciplinary support networks would support and foster communication and provide practical guidance to HCPs and also support patients through their journey. Encouraging regular exchanges of knowledge and discussion can support collective learning and empower professionals.
- Involving HCPs from across the roles included in this study in advisory roles or a steering group for the design of the research study would support sustained engagement. This could ensure views are continually integrated into the programme (and early design) and provide the opportunity for HCPs to contribute at all stages of the research.

4.3. Conclusion

Overall, HCPs working in adult population healthcare in the NHS in England are optimistic about the potential benefits of using genomics in healthcare. This enthusiasm is balanced by concerns around practical readiness and changes needed across and within the system. The recommendations in this report emphasise that, to ensure effective implementation, the research study should be embedded in NHS structures in England; while engaging with public health provision that occurs outside the health service; embedding a commitment to equity; building and maintaining trust through clear communication; and providing practical support for HCPs and patients.

Engaging HCPs across the roles considered here requires careful consideration of timing, flexible participation options, direct recruitment strategies, and sustained opportunity. Introducing and using genomic testing and information in this way would represent not only a scientific and innovation advancement, but also complex organisation and system change. Success will depend as much on addressing professional, infrastructural and ethical considerations as on the continued development of the field of genomics and understanding of how genes influence health.

This report is complemented with reports on the two other engagement strands within Genomics, Healthcare and You: the inclusive communities and public dialogue reports. An overarching report brings together the findings from across the engagement programme.

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