Community Perceptions of The Generation Study:

Birmingham Case Study Insights

STRAP

STRATEGIC CONSULTANTS

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Table of Contents:

Page

2. Executive Summary
4. About STRAP
5. Introduction
7. Ethnic Minority Health Inequalities
12. The Generation Study
14. Medical Scepticism Among Minority Communities
19. Methodology
26. Key Findings
48. Conclusion
52. Policy Recommendations
54. Endnotes & Acknowledgements

Please note:

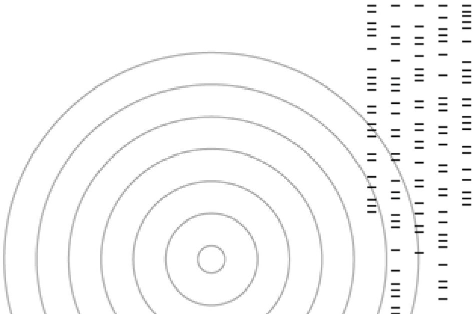
This document contains interactive elements such as **QR codes** (to be scanned) and **video links**.

For **video links**, please see the following icons. ▶

Executive Summary

This report represents a groundbreaking collaboration between **STRAP Consultancy UK**, Genomics England and the NHS Central and South Genomic Medicine Service Alliance, exploring the perceptions and attitudes of Muslim communities in Birmingham towards genomic medicine and research. Led by Dr Anthony (Abdul Haqq) Baker, STRAP employed an innovative, community-embedded methodology - PAVE (Peer Audio Visual Engagement) to foster genuine engagement and trust-building among often marginalised communities.

The aim of the consultation process was to understand Muslim community perceptions of genomics, with a focus on their ethical concerns and practical barriers to engagement. In doing so, the report seeks to address long standing health inequalities and advocate for equity in access to emerging health technologies and systemic marginalisation.



It explores the nuanced interplay between community trust, health equity, data ethics and genomic literacy through the lens of the Generation Study, where the participation of communities in a national research study aiming to screen 100,000 newborn babies for over 200 rare genetic conditions remains optional.

The exercise acted as a catalyst for meaningful dialogue between minority communities, researchers and statutory institutions. The PAVE model created safe spaces for peer-led visual storytelling and facilitated deeper cultural sensitivity, mutual respect and reciprocity. Participants were not treated as mere subjects, but as change-makers, co-creating narratives that reflected their lived realities and concerns.

The report serves as a blueprint for inclusive health research practice and demonstrates how partnership with trusted community organisations like STRAP can bridge gaps between statutory bodies and build community agency. It is hoped that this approach sets a model for future faith and race inclusive, genomic medical research.

10 Key Messages

Trust in genomic screening is conditional. While participants appreciate NHS-led initiatives, concerns around data security and future misuse remain widespread.	Ethical concerns are multi-layered spanning informed consent, data ownership, intergenerational responsibility and commercial exploitation.
Representation matters. Participants highlighted the lack of ethnic, linguistic, and cultural visibility in educational materials as a barrier to trust.	Participants expect more transparency regarding how genomic data will be stored, governed and possibly shared with third parties.
The emotional impact of screening decisions is profound, particularly for parents and carers, who express fear, guilt and protective instincts.	Historical memory and lived experience shape ethical perceptions with references to past abuses influencing current scepticism.
Community engagement should be localised and culturally tailored, incorporating religious, familial, and community-specific perspectives.	Video-based education is effective but insufficient. Participants requested more interactive and personalised communication tools.
Equity and access must be central to implementation ensuring marginalised groups are neither overlooked nor over-targeted.	Recommendations must be action-oriented, reflexive and informed by ongoing dialogue and not one-off consultations.

About STRAP

Strategic, Tactical, Regional Alliance & Partnership

STRAP is a pioneering consultancy at the intersection of research, advocacy and public service engagement founded and led by Dr Anthony (Abdul Haqq) Baker. Dr Baker is an award-winning, internationally recognised thought leader and academic with practitioner expertise spanning more than 30 years in community leadership and transformation. The mission of STRAP is to empower communities, especially those affected by systemic injustice within areas often overlooked by mainstream research, such as faith, race and socio-economic inequality.

It encourages transformative change by highlighting marginalised voices that can shape health innovation, education and public policy through trust-based, evidence-led partnerships. It has successfully cultivated trusted networks among diverse communities globally through pioneering tools like PAVE and has opened spaces for minority communities to speak, question, learn, lead and create positive impact. STRAP invites statutory bodies, funders and academic institutions to partner in radically inclusive research. With a proven ability to navigate both community dynamics and institutional expectations, STRAP remains a trusted conduit for those who have too often been overlooked at a time when equity should inform policy.

Introduction

Genomics England and NHS Central and South Genomic Medicine Service Alliance collaborated with STRAP to deliver a community-focused consultation in which participants engaged with information about genomic healthcare. It captures the findings of a half day event held in Edgbaston, Birmingham on 22nd May 2025.

The goal of this exercise was to explore the interplay between community trust, health equity, data ethics, and genomic literacy through exposure to the Generation Study, a national initiative aiming to screen 100,000 newborn babies for over 200 rare genetic conditions. The report draws upon a robust corpus of quantitative (survey) and qualitative (video discussion transcripts) data, which analyses congruences and variances among participants.

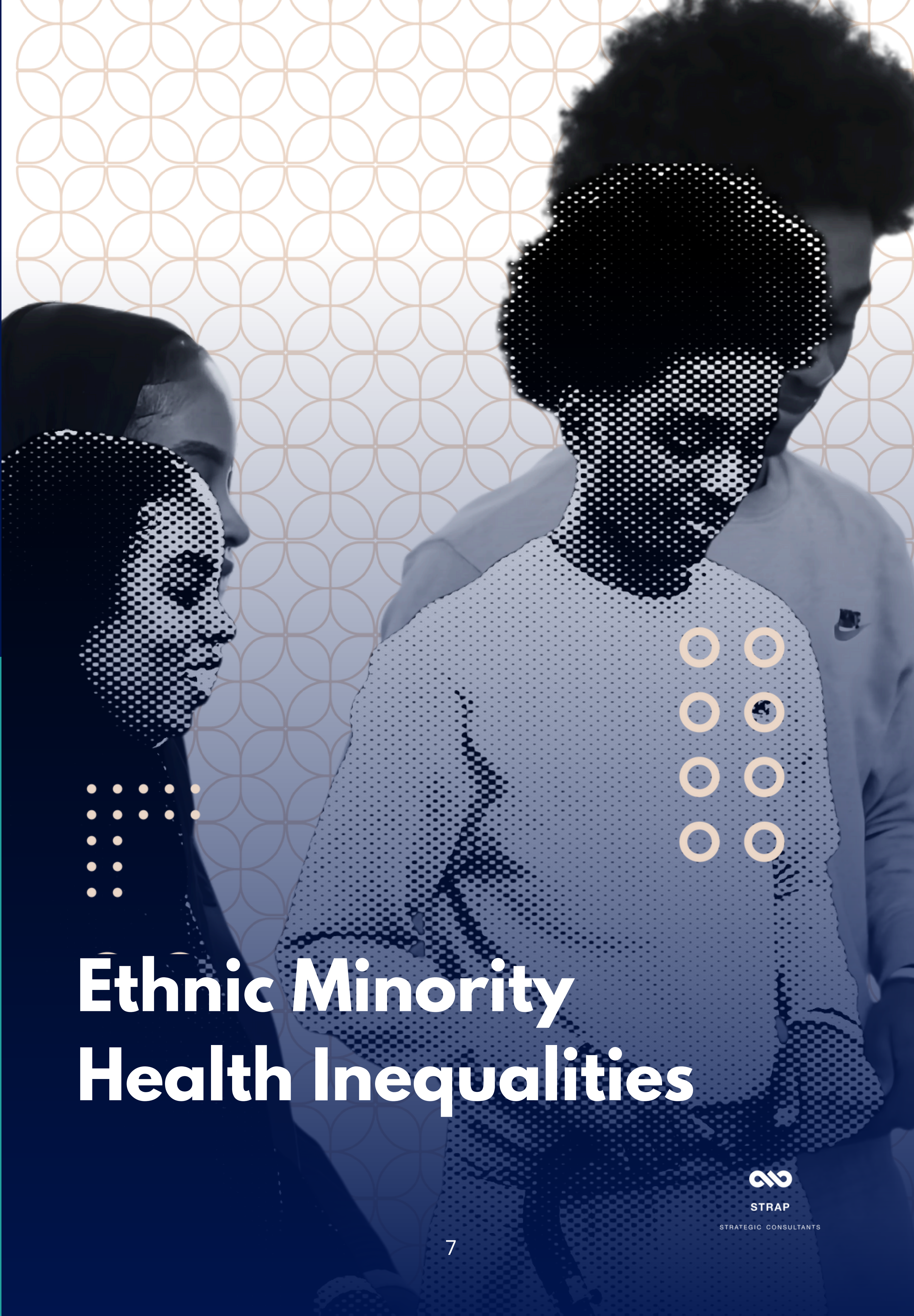
Unlike conventional focus group settings, an alternative, more innovative approach - Peer Audio Visual Engagement (PAVE) - was used to facilitate active and organic participant engagement. PAVE is a method of facilitating community-led engagement and discussion which allows a diverse and rich source of qualitative and quantitative data to be gathered and analysed. It surveyed initial participant responses, produced creative outputs and collated audiovisual recordings of group discussions before triangulating the two data sources with relevant literature in the field of genomic research.

Genomics is reshaping predictive healthcare and early diagnostic capabilities. However, legitimate questions about the social contract of medicine, politics of data and the legacies of exclusion in health research are increasingly being raised. The Generation Study is emblematic of this duality as it provides assurances of clinical advancement while demanding careful navigation of ethical terrains. This report addresses the dialogical interface between medical science and community realities and concerns. Using a mixed method research approach, it provides an overview of how some communities, particularly ethnic minorities, interpret and respond to the Generations Study.

The intended audience for this report includes medical professionals, academics and grassroots stakeholders. It showcases examples of active participant engagement alongside insights that can serve as a useful resource to identify new and existing challenges surrounding the awareness of genomics while also providing potential solutions to existing knowledge gaps. It aims to respond to the following questions:

- What are the prevailing perceptions of genomics and genetic screening among Muslim communities?
- How do participants respond to NHS educational content in terms of clarity, trustworthiness and relevance?
- What ethical concerns dominate and how do these align or diverge from survey responses?

This report commences by highlighting ethnic minority health inequalities thereby setting a wider context for The Generation Study and the potential barriers to engagement due to medical scepticism among Muslim communities. The methodologies used by the STRAP team are described and the subsequent analysis, findings and recommendations form the core of the report.



Ethnic Minority Health Inequalities

Ethnic Minority Health Inequalities

Health inequalities among minority communities in the UK are well-documented and continue to persist. Ethnic minorities experience disproportionately poorer health outcomes compared to the White British population despite being identified over many years. The Marmot Review (2020) highlighted how social determinants such as income, education, housing, and employment significantly contribute to these disparities, with minority groups concentrated in economically deprived areas. The Public Health England (PHE) report on Disparities in the Risk and Outcomes of COVID-19 (2020) further demonstrated how Black, Asian and Minority Ethnic (BAME) communities suffered higher rates of COVID-19 infection, hospitalisation, morbidity and mortality. Structural racism, unequal access to healthcare, language barriers, and medical mistrust exacerbate these inequalities. Studies like the Ethnic Health Inequalities and the NHS – Driving Progress in a Changing System, (2021), focus on how systemic discrimination leads to delayed diagnoses, poorer mental health care, and substandard patient experiences for ethnic minorities. Addressing these disparities requires targeted, culturally sensitive health policies, improved data collection and sustained efforts to dismantle structural barriers within the NHS and wider society.

Faith Based Health Disparities

British Muslims, as a religious group, face a range of different health challenges, linked to socio-political factors such as Islamophobia, racial discrimination and socio-economic disadvantage and stretch back several decades. Research indicates that the 2005 London bombings exacerbated psychological distress among Muslim communities, with many reporting heightened anxiety and depression due to increased stigma and social exclusion.[1] Additionally, negative media portrayals contribute to chronic stress and lower self-esteem among Muslim individuals, particularly young people. [2] Cultural barriers also prevent many from seeking help, including stigma within communities and limited access to culturally competent mental health services.[3]

Maternal and Reproductive Health

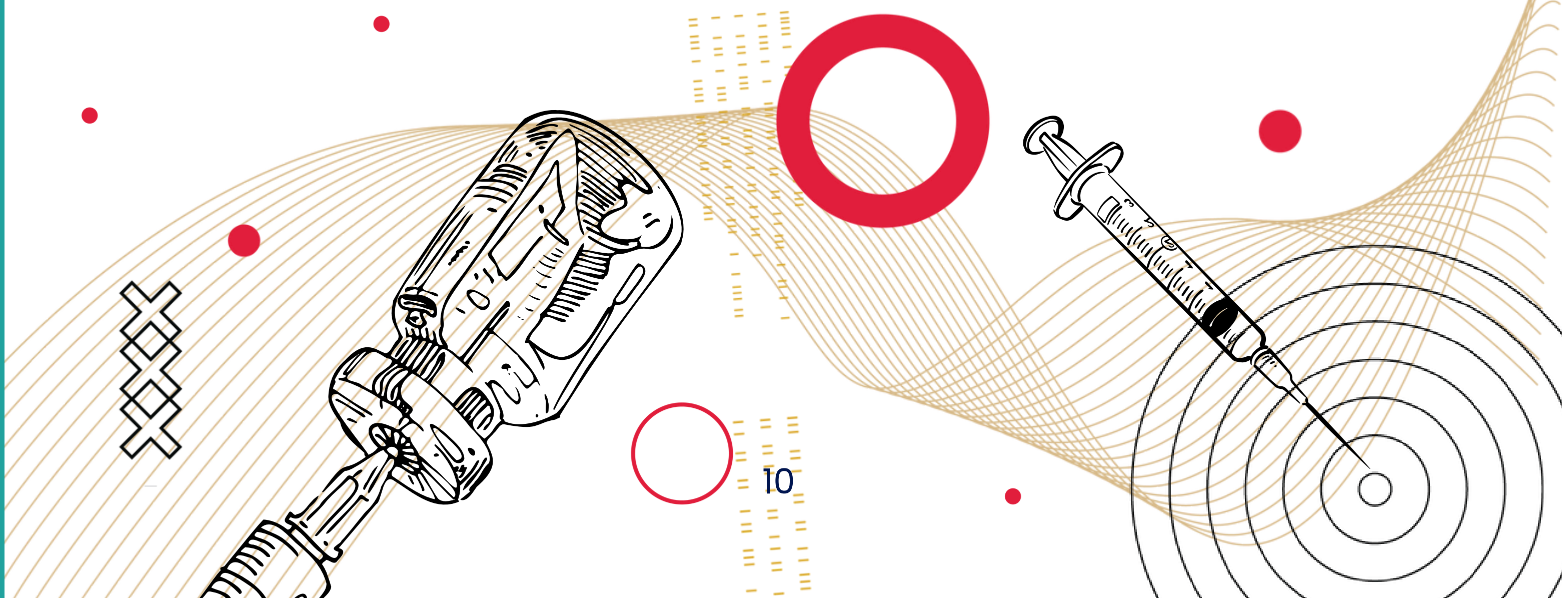
Maternal health outcomes among British Muslim women, particularly those of South Asian heritage, reveal persistent inequalities when compared to the general population. Studies show higher rates of maternal mortality and severe morbidity, attributed to socio-economic disadvantage, language barriers, and inadequate antenatal care.[4] Many Muslim women report feeling misunderstood or overlooked by healthcare providers, which can delay treatment or discourage engagement with prenatal services.[5] Religious and cultural preferences, such as gender-sensitive care and modesty concerns, are often not adequately addressed in standard maternity services, contributing to dissatisfaction and poorer health outcomes.[6]

Diabetes and Chronic Illness

British Muslims, especially those of South Asian origin, experience disproportionately high rates of type 2 diabetes and related metabolic disorders. Evidence shows that even without a formal diagnosis, South Asian individuals have higher baseline HbA1c levels, indicating early metabolic dysregulation and increased risk.[7] Genetic predisposition, lifestyle factors, and dietary habits contribute to this disparity, compounded by limited awareness and delayed screening in some communities.[8] Additionally, socio-economic deprivation, low health literacy and lack of culturally appropriate prevention programmes hinder effective disease management.[9]

Cardiovascular Disease

Cardiovascular related illness continues to be a major cause of morbidity and mortality among British Muslims, particularly those of South Asian heritage. Compared to the general population, South Asian Muslims exhibit a significantly higher risk of coronary artery disease, hypertension, and stroke, often at younger ages.[10] This elevated risk is attributed to a combination of genetic susceptibility, lifestyle factors such as physical inactivity and poor diet, and psychosocial stressors like discrimination and economic hardship.[11] Despite this, preventive measures and early detection strategies are often underutilised in these communities, partly due to a lack of culturally relevant messaging and outreach.[12]



Structural Inequalities

Structural Inequalities Discrimination on the basis of race and manifests in nearly every aspect of public life and is structural. Historic racism and poorer experiences of healthcare at work means that many BAME groups lack trust in NHS services. This has resulted in a reluctance to seek care on a timely basis, and often, late presentation of advanced stages of illness. A recent example of the widespread impact of structural inequalities is illustrated by the fact that BAME groups made up a fifth of England's Corona virus related hospital deaths in April 2020.

Religious and Racial Discrimination

Discrimination based on religion and ethnicity plays a critical role in shaping the health outcomes of British Muslims. Structural racism, social exclusion, and institutional bias affect access to quality healthcare, employment opportunities, and housing which are key determinants of health equity.[13] These systemic issues contribute to chronic stress, poorer emotional health, and reduced trust in public institutions, including the National Health Service (NHS).[14] Muslim patients often report being treated differently in healthcare settings due to their religion, leading to delays in seeking care and suboptimal treatment.[15]

The Generation Study

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The Generation Study

The Generation Study, launched by Genomics England in partnership with the NHS, is part of the newborn genomes programme research study aiming to explore the utility and feasibility of using whole genome sequencing as a screening test for over 200 rare genetic conditions in newborn babies, to understand whether we can improve the ability to diagnose and treat genetic conditions in the future. Historically, genomic research has been disproportionately focused on individuals of European descent, which has led to gaps in understanding how genetic conditions manifest across diverse populations. The Genomics Generations Study actively addresses this imbalance by encouraging participation from all ethnic backgrounds. By doing so, it improves the chances of identifying rare disease mutations that may be more prevalent in certain ethnic groups, such as those found in South Asian, African-Caribbean, and Arab communities.

The Generation Study is testing for rare genetic conditions that usually appear in the first few years of life. They can be improved and treated, if detected early, through the NHS. Beyond diagnosis, the study supports personalised treatment plans tailored to an individual’s genetic profile, which is especially important for conditions where drug responses vary by ethnicity.

Visit: Newborn Genomes Programme | Genomics England

Medical Scepticism among Minority Communities

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Medical Scepticism among Minority Communities

STRAP's research has identified that the Generation Study arrives in a historical and social context marked by deep-seated scepticism among many BAME communities. This caution is not unfounded but rooted in both past injustices and contemporary missteps that have undermined trust in medical and government institutions. One of the most troubling historical events was the forced virginity testing of Asian women arriving at UK borders in the late 1970s. Conducted under the pretext of immigration control, these invasive procedures were implemented without proper consent and reflected an egregious breach of bodily autonomy and racialised surveillance. This event remains a symbolic touchpoint, particularly for British Muslim South Asian women and highlights the power imbalances that persist in institutional practices.

Similarly, the radioactive 'chapati' experiments of the 1960s and 70s – wherein the UK government administered radioactive isotopes in food without participants' informed consent – is another example of unethical experimentation disproportionately targeting marginalised groups. These actions, exposed decades later, revealed an exploitative approach to medical research, often lacking transparency, cultural sensitivity, or community oversight. More recently, the COVID-19 pandemic reignited scepticism. While vaccine rollout was broadly successful, reports of under-reported side effects – especially among people with existing health vulnerabilities – fuelled concerns. Anecdotal experiences shared in community forums and social media, particularly those involving severe reactions or lack of post-vaccine support, amplified a sense of being overlooked by the healthcare system.

These legacies are compounded by lived realities of health inequity. Many BAME communities report ongoing disparities in diagnosis, treatment, and outcomes – particularly in areas such as maternity care, mental health, and chronic disease management. There is evidence to show that poor engagement between service users and health care staff has a negative effect on access to services and on the development of relationships between service users and professionals.

The need to reduce inequity and improve access to health care for BAME communities has been recognised in recent years with significant development of policies and practices to overcome cultural incompetence and improve engagement. The cumulative effect is a cautious, if not adversarial, posture toward new initiatives, particularly those involving long-term data storage, emerging technologies, or unclear benefit pathways. The Muslim Census online survey of 1,007 British Muslims aged between 18-65+ sought to identify whether perceptions towards health research and genomics are based on fact. Findings from this, together with this report, are particularly important today in light of heightened concerns following the government's recent announcement to invest £650 million by 2030 in Genomic Medicine in England, which will include the ambition of mapping the DNA of every newborn baby in England using Whole Genome Sequencing (WGS).

The Generation Study raises several ethical and practical concerns. These include potential discomfort to babies during sample collection, the possibility of incorrect data, and the impact of potentially far-reaching results. Other concerns involve the long-term implications of storing and using genomic data, the potential for discrimination based on genetic information, and the complexity of informed consent for the duration of a long-term, open-ended study. More specific concerns include:

Ethical Issues:	**Practical and Clinical Concerns:**
Informed Consent: The study's open-ended nature and potential for future uses of genomic data raise questions about whether parents can truly provide informed consent for their child's participation.	**Data Analysis and Interpretation:** The vast amount of data generated requires sophisticated analysis and interpretation, with a potential for errors and misinterpretations.
Data Privacy and Security: Existing concerns about the potential for breaches of privacy, unauthorised access to data and the possibility of discrimination based on genetic information.	**Inconclusive Determinants:** Challenges to determine whether a detected genetic variant will lead to a disease, and what level of further, possibly more invasive testing and monitoring will be required.
Unintended Outcomes: The implications of receiving unexpected or uncertain results, especially for rare conditions, requires careful consideration.	**False Positives/Negatives:** The potential for false positives or negatives in genomic testing needs to be effectively addressed.
Commercial Use: Concerns surrounding the potential for commercial exploitation of the genomic data collected.	

Social and Psychological Concerns:	**Study Design and Implementation:**
Anxiety and Stress: Receiving news of a potential genetic condition can significantly impact families, heightening existing fears.	**Diversity and Inclusion:** Ensuring the study is inclusive and representative of diverse populations is vital.
Discrimination: There is a risk that genetic information could be utilised to discriminate against individuals socio-economically in areas like education or employment etc.	**Integration with Healthcare:** The study needs to be carefully integrated with existing healthcare systems and newborn screening programmes.

The above-mentioned contexts demand that genomic initiatives, like the Generation Study do more than disseminate information; they must actively acknowledge past malpractice, engage in culturally competent dialogue, and co-create consent and governance frameworks with communities they aim to engage.

Methodology

Methodology

Members of the Muslim community in Birmingham were invited to participate in this study using STRAP Peer Audio Visual Engagement (PAVE), model to facilitate community-focused, (as opposed to community-targeted,) engagement, the former enabling grassroot-led interventions instead of the familiar and traditional top-down hierarchical approach whereby participants are often the subject of extractive research from external bodies.

Community engagement officers embarked on a short-term campaign to visit mosques and community centres raising awareness about the session and its collaborative remit with the Genomics Generation Study. The objective of PAVE in this study was to engage with identified community-based focus groups on creative outputs/videos that are likely to impact them and their respective communities. The facilitatory process would promote participation in open, safe spaces via discussions after viewing appropriate creative outputs.

Participant outreach followed a multi-modal strategy comprising:

- Community flyers and posters
- Targeted email communications
- A dedicated registration host page
- Social media campaigns disseminated across cultural, community, and faith-based platforms

Importantly, individuals who registered interest were personally contacted by the STRAP team. These structured pre-event calls offered space to explore the event content, running order and goals, while also addressing any concerns. Participants were given the opportunity to speak openly about the implications of the Generation Study, the relevance of genomics to their lived experiences, and how their voices would be integrated. This level of care reflected an intentional departure from top-down approaches affirming participants' positions as co-designers of the research process.

All participants were required to have good proficiencies in spoken and written English to fully engage with the audiovisual content, questionnaires and entirety of the PAVE sessions.

Incentivisation was provided in the form of vouchers in recognition of attendees' participation. Refreshments, together with a child-friendly atmosphere faciliated participants who were accompanied by children.

The MAC venue was strategically selected in view of its central location and close proximity to various communities. It also allowed for a neutral, non-NHS/non-institutional environment with good transport links.

Attending the PAVE event required substantial personal commitment from participants. The session lasted up to three hours, and many incurred out-of-pocket costs such as parking and travel expenses. The project’s ability to attract and retain attendance, despite these barriers, highlight the strength of the community engagement model and the ethical imperative to value voluntary contributions, especially in historically underserved populations.

One particularly poignant example emerged in the participation of a postpartum mother, who contacted the STRAP team while still in the hospital four days after giving birth to a premature baby with genetic complications. During her call, she voiced her desire to attend the PAVE session if medically cleared, to represent herself and mothers like her. Her newborn was born with rare genetic disorders and was the reason she felt the research was not just significant, but urgent. Her decision to attend was an act of advocacy, both deeply personal and profoundly political, intended to ensure mothers like her were neither overlooked nor voiceless in genomic policy discourse.

Such cases underscore the centrality of care, sacrifice and lived experience in this research design. It affirms that participatory genomics cannot be reduced to attendance metrics, it must actively centre those who embody the stakes.

PAVE Format and Procedure

Participants were divided into four separate groups with each being assigned a specific room to engage in PAVE, focusing on a specific creative output. Respective groups would observe the selected creative output and individually complete a designated PAVE questionnaire without consultation with other members at the initial stage. Once complete, participants would no longer have access to this primary data and proceed to the 2nd stage of open dialogue with group members. This particular stage involved the room facilitator for each group prompting open discussion among participants whereby thoughts and ideas, alongside possible converging or diverging ideas would be aired.

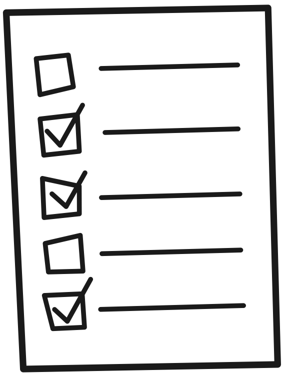
Audio and visual recordings would capture this stage, the objective of the 2-pronged process being to provide additional information as to whether subsequent group consultation amounted to a divergence of views or conversely, groupthink, resulting in a reversal of earlier individually recorded views (via the PAVE questionnaire).

On completion of the above (individual and collective review) in the respective rooms, each group would proceed to a new room to repeat the process with another creative output/video until they had completed a total of 4 viewings. The conclusive stage of PAVE engagement would involve the 4 groups converging to discuss and prioritise the creative output/s that most impacted them individually, highlighting the rationale behind their choices/prioritisation.

The entire process was audio-visually recorded, with both individual and group reflections captured for thematic analysis. The dual-layer structure (individual first, group second) allowed the research team to track divergences between private responses and public discourse, illuminating how group settings influenced expression.

A convergent parallel mixed-methods design was also employed:

Quantitative survey data (collected via Google Forms and stored in Sheets) were descriptively analysed, including:



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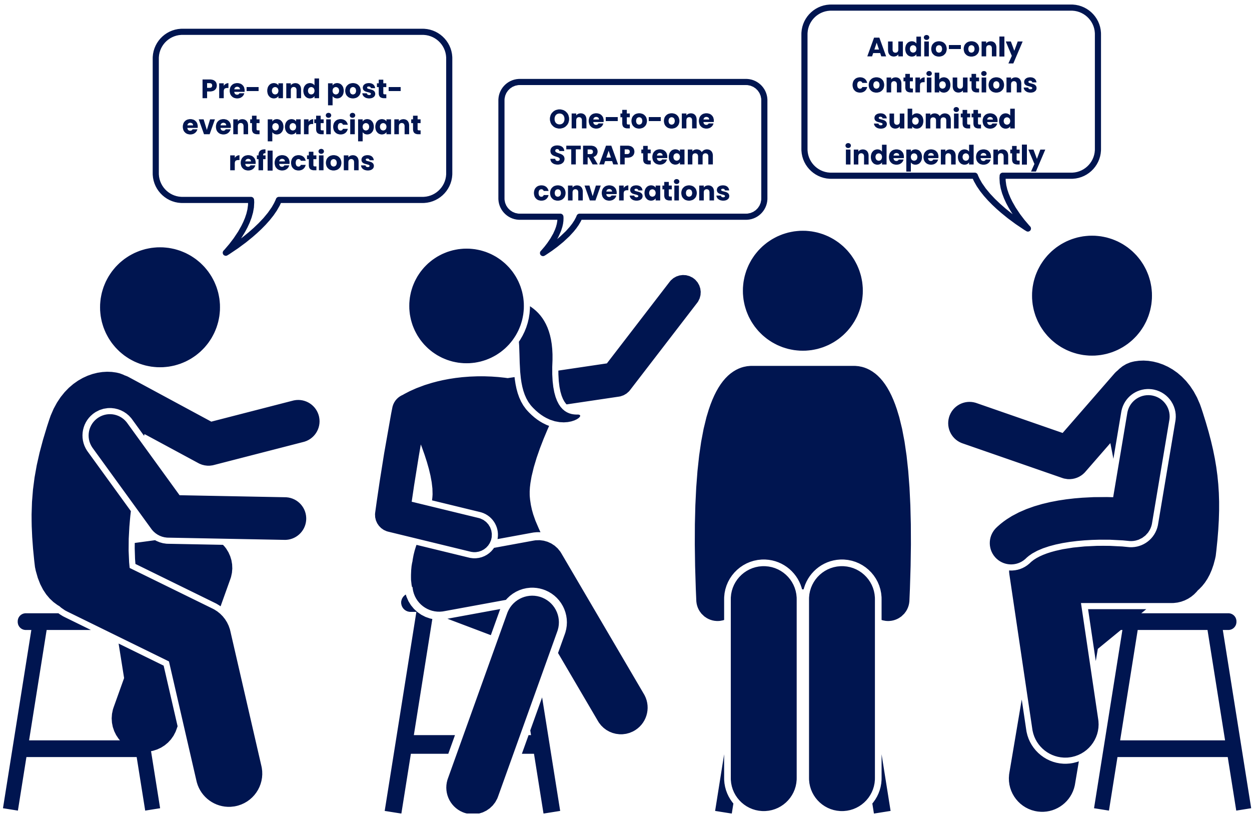
survey responses

Disaggregated insights into trust, representation, consent concerns, and emotional impact

Qualitative data from video transcripts and group recordings were analysed through AI-assisted thematic coding, reviewed and refined by STRAP researchers

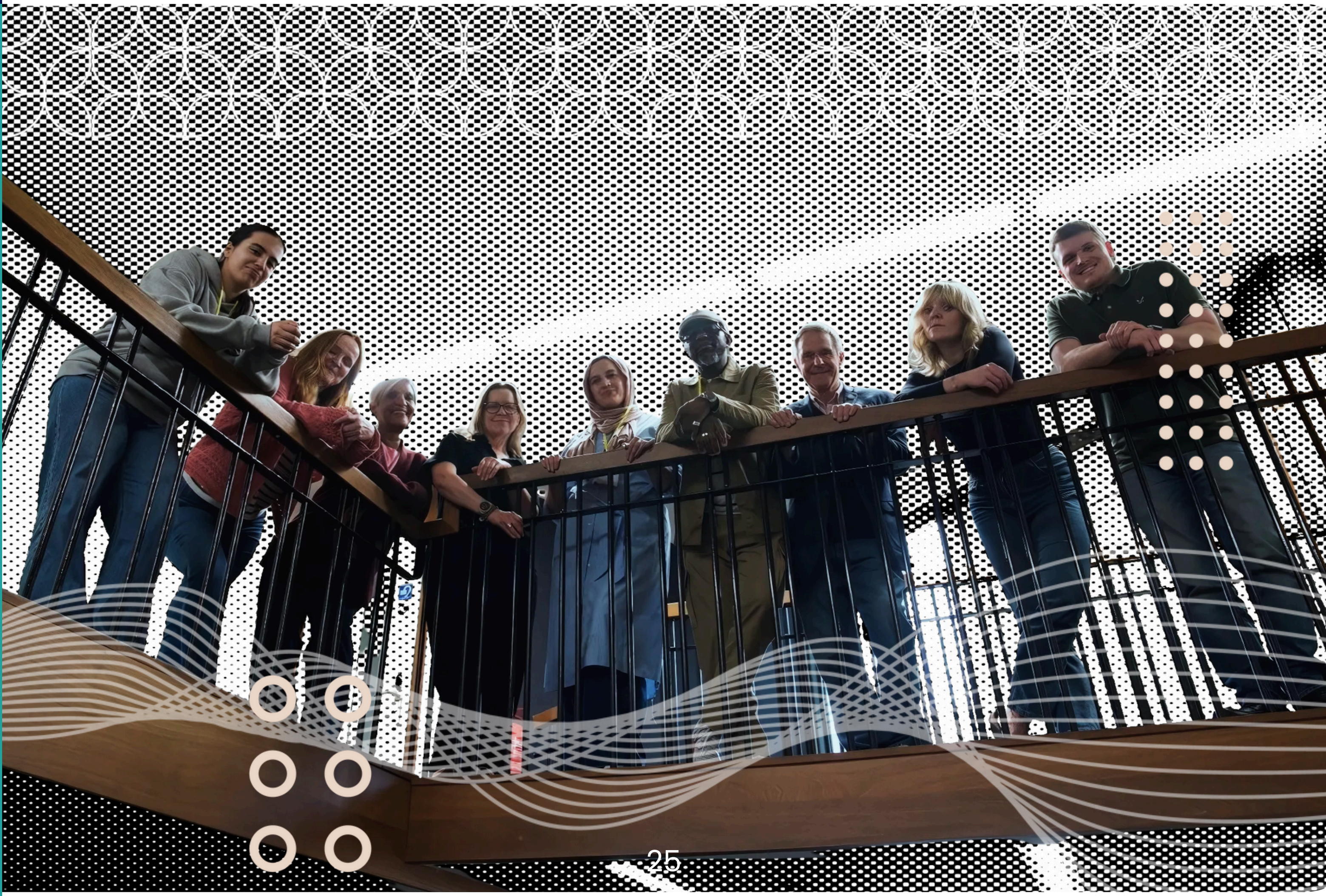
Supplementary sources included:



- Pre- and post-event participant reflections
- One-to-one STRAP team conversations
- Audio-only contributions submitted independently

This layered approach enabled triangulation of insights, ensuring that emergent themes were not isolated anecdotes, but recurring patterns grounded in lived experiences. The following tools and approaches were used in the process of analysing the data generated from this exercise. A convergent parallel mixed-methods approach was utilised and survey data was descriptively and inferentially analysed while qualitative data obtained from video session transcripts underwent thematic analysis through specially designed AI software alongside further dissemination from the authors of this report.

The PAVE methodology is structured to yield qualitative data from peer group discussions following individualised input via online questionnaires designed to elicit responses for solely quantitative purposes. Qualitative data is obtained from audio-visual recorded sessions, which are then transcribed for review and analysis.



Key Findings

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Interactive Live Data

An Introduction to Peer Audio Visual Engagement (PAVE)

REALTIME FINDINGS

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Scan the Code.

Click **HERE** to view the live interactive report.

Welcome to the Interactive Looker Studio Report

This live dashboard is designed to help you explore and analyse insights from different creative outputs and participant groups. Whether you are interested in a single creative output or comparing feedback across groups, the built-in filters give you control over what you see.

Use the Creative Output Title and Group Number filters to focus your view, and explore the data in a way that is relevant to your needs. You can even use advanced filter types like Equals, Contains, or Regex to refine your results.

Follow the steps to get started.

How to Use the Live Looker Studio Report

This interactive report lets you filter data based on two key options: **Creative Output** Title and **Group Number.**

You can use advanced filters to drill into the data. Here's how:

1. Creative Output Title Filter

This allows you to focus on specific creative projects:

Available titles include:

- Invisible – Be Invisible
- World Health Organisation
- GE Diverse Data
- Genomics – Are we staring into the abyss

When you click the filter box, you'll see different filter types:

Filter Type	What It Does	Example Input	Result
Equals	Shows only exact matches	GE Diverse Data	Only that exact title
Contains	Shows anything that includes the phrase	Health	Matches "World Health Organisation"
Starts with	Shows titles beginning with your input	Genomics	Matches "Genomics – Are we staring into the abyss"
Regex	Allows advanced pattern matching (regular expressions)	.*Health.*	Matches any title containing "Health"
In	Matches any from a comma-separated list	Invisible – Be Invisible, GE Diverse Data	Returns both titles

Tip: Use Contains or In for more flexible selection if you're unsure of the full title.

2. Group Number Filter

Choose which group(s) of participants you'd like to view:

- Group 1
- Group 2
- Group 3
- Group 4

Filter Types Work the Same Here:

Filter Type	Example Input	Result
Equals	Group 2	Shows only Group 2
Contains	Group	Shows all groups
Starts with	Group 1	Shows only Group 1
In	Group 1, Group 3	Shows both Group 1 and Group 3
Regex	Group [12]	Shows Group 1 and Group 2 (uses pattern matching)

3. See Results Instantly

Once you apply your filter(s), the report will automatically update to reflect your selection — no need to click anything else.

Resetting Filters

To remove your selections and start again, click the ✕ (clear) icon next to each filter.

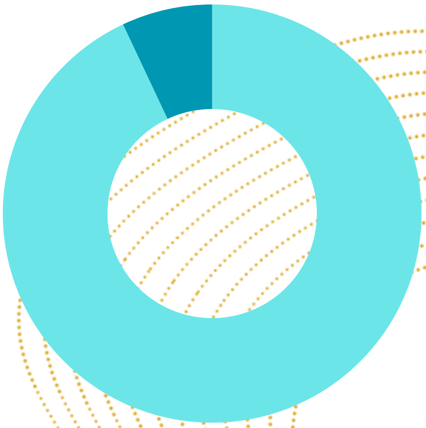
Key Findings

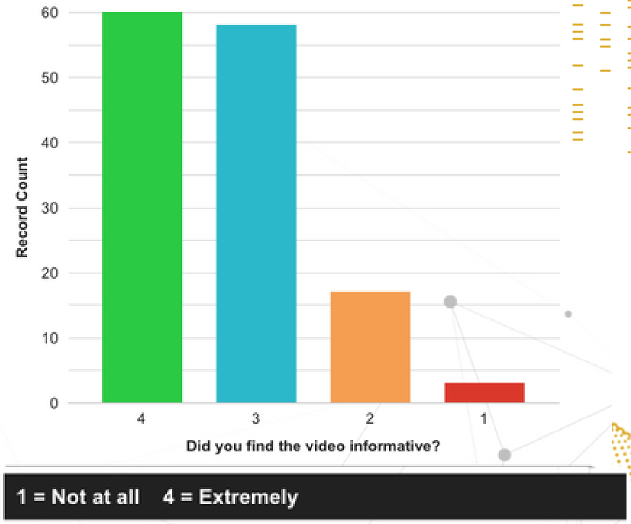
Using thematic and statistical approaches, the report focuses on four domains:

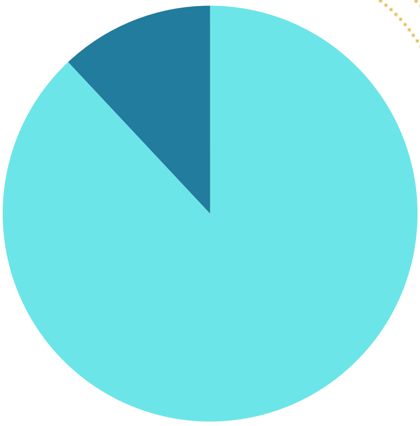
1. Trust in genomic medicine and institutions.
2. Public reactions to educational video content.
3. Ethical and inclusion-based concerns.
4. The role of identity and lived experience in shaping responses.

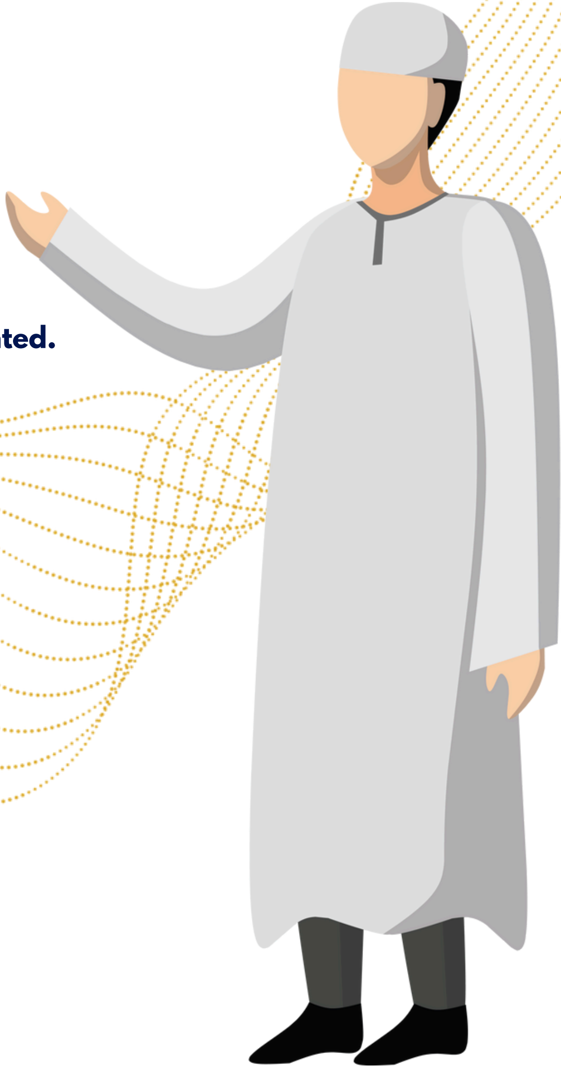
The insights serve both policy formulation and community mobilisation purposes, with clear implications for consent protocols, communication strategies, and future engagement models. Respondents frequently noted support for screening but expressed unease around long-term data governance.

Reactions to Creative Outputs



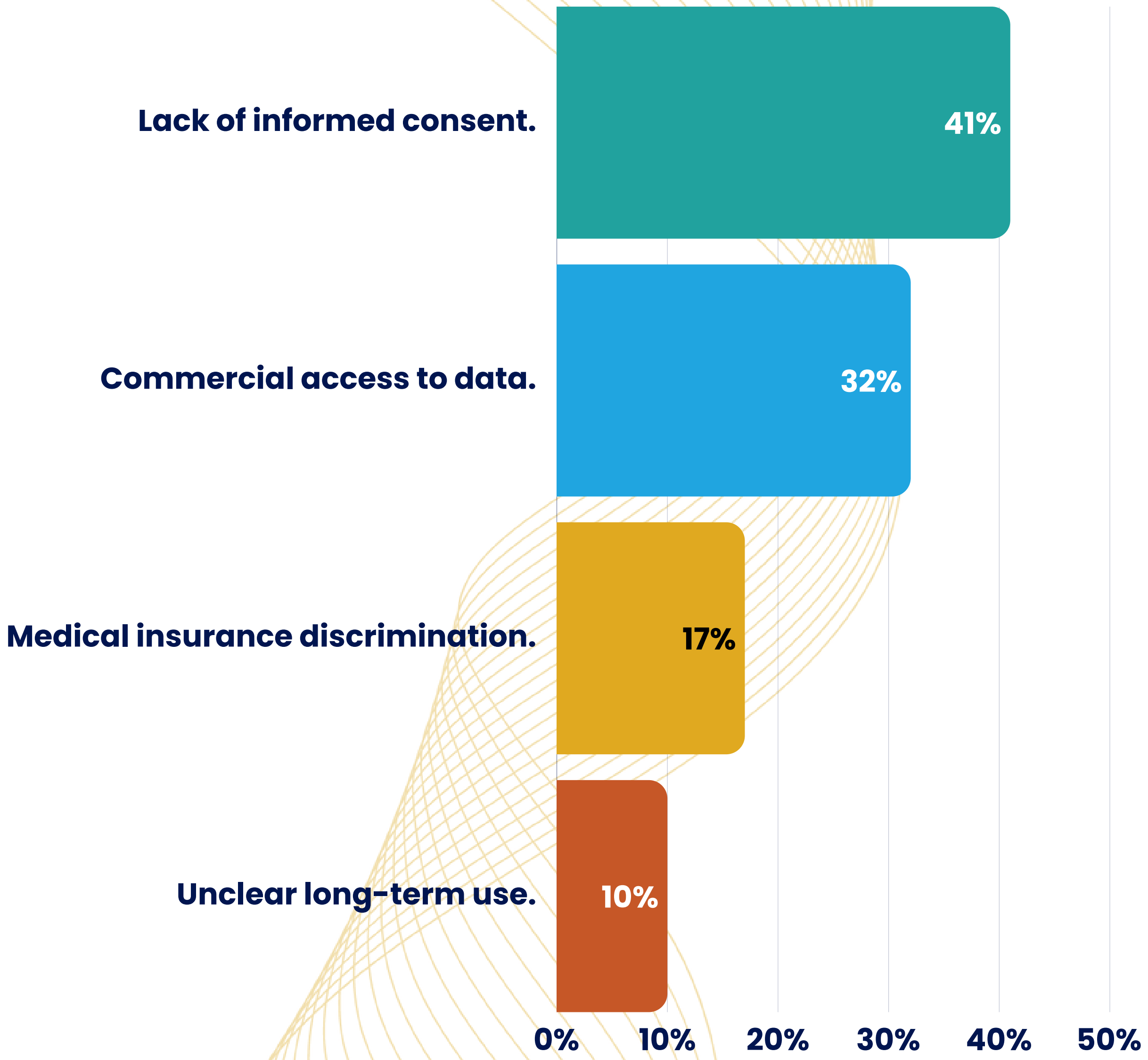






Ethical Risk Perception

Respondents were asked to rank ethical concerns:



It is clear that participants continue to have concerns surrounding the use of personal data, its potential misuse for commercial purposes, alongside discriminatory practices based on socio-economic status.

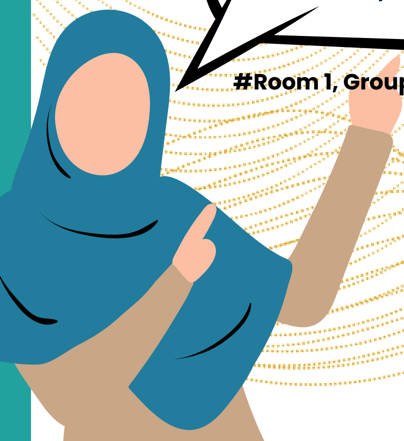
Qualitative Insights from Video Transcript Analysis

Themes From Group Discussion:

- Conditional Trust based on previous experience.
- Health Equity and Structural Disadvantage.
- Trust.
- Consent, Data and the Digital Divide.
- Emotional Potential/ Future Trajectories.

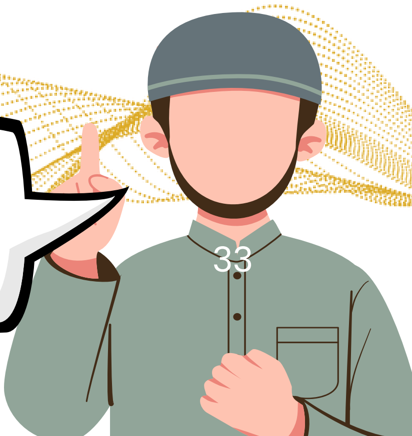
> ***...seeing someone who looks like me, talking about this issue and the platform and the scale of what this could do, what this could become.***

#Room 1, Group no.1, Video - Invisible be visible, 10:32



> ***I'd love to be involved but have not seen anything like this happening in my community. Genetic research has been used against people like me...***

#Room 2, Group no.1, Video - Invisible be visible,00:54



Positively Valued Aspects:

NHS leadership of initiative.

Early detection as proactive care .

Potential to address inherited conditions in advance -

This isn't just about health. It's about who holds our future in a file.

#Room 4, Group no.4, Video - Are we looking into the abyss, 06:31

...there's a cultural nuance there that is around storytelling which you know is no difference between the people like the black or white or you're Muslim.

#Room 1, Group no.1, Video - Invisible be visible, 11:31

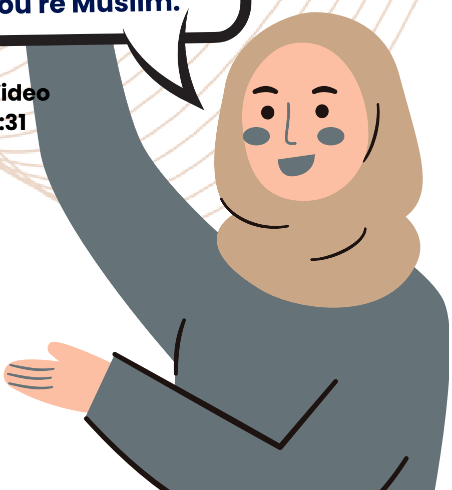
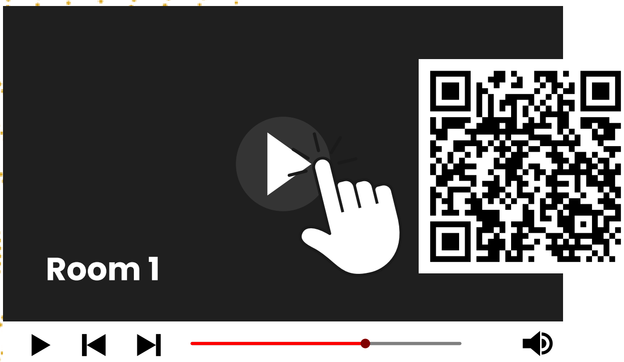


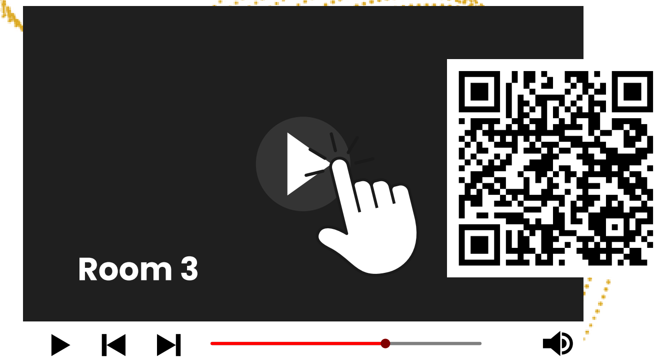
Table 1: Thematic Impact on Participant Groups in Rooms

Theme	Room 1(video)	Room 2 (video)	Room 3 (video)	Room 4 (video)
Conditional Trust	High	Medium	High	Medium
Representation Concerns	High	High	Medium	High
Ethical Anxiety	Medium	High	High	Medium
Enthusiasm for Screening	High	Medium	Medium	High

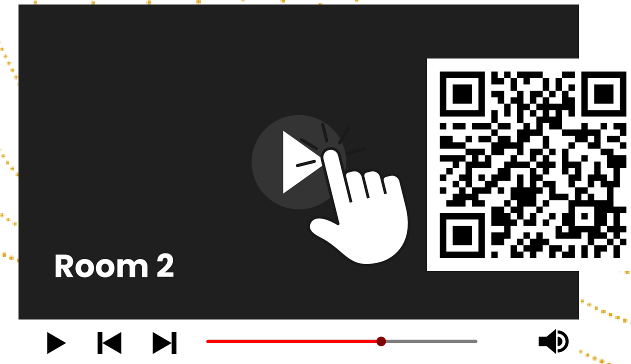
Cross-Room Comparative Themes



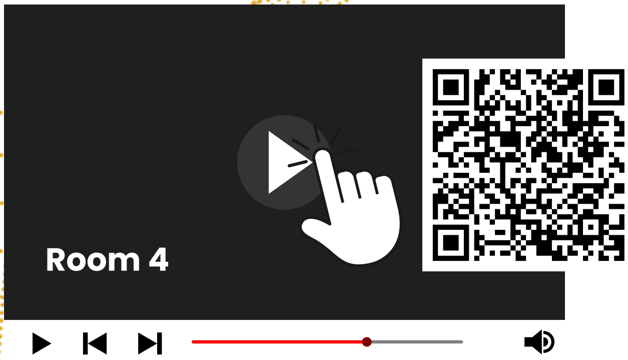
Video Output 1:
Invisible - Be Invisible



Video Output 3:
GE Diverse Data



Video Output 2:
World Health Organisation



Video Output 4:
Genomics - Are we staring into the abyss

Confidence & Trust Across Rooms

Participants in Room 1 tended to link their trust in the NHS with personal and community experiences. Room 2 included voices more sceptical of institutional change. Room 3 featured a mix of cautious optimism and intergenerational concerns, while Room 4 highlighted concern around digital privacy.

> *I work in care - I see both good and bad, but this is asking for long-term trust with very little detail.*
>
> **#Room 3, Group no.3, Video - DNA Genomic video, 20:22**

Participants referenced the cultural framing of the videos. Rooms 1 and 4 raised concerns over the use of “neutral British accents” and a lack of religious or ethnic context. Room 2 questioned whether the visuals would reach non-English-speaking populations effectively.

> *It’s informative but not reflective - it doesn’t sound like how we talk at home.*
>
> **#Room 2, Group no.1, Video - World Health Organisation ,1:19**

In Room 1, the conversation began with questions about consent but deepened into discussions of power and bio-governance. In Room 3, ethical concerns were often contextualised with examples of data misuse in other sectors, such as predictive policing and welfare systems.

> *How do you even begin to explain to your child that their data has been with the government their whole life?*
>
> **#Room 4 , Group no.3, Video - Are we staring into the abyss? 12:21**

These observations echo broader socio-political sentiment located in academic discourse regarding surveillance capitalism and the erosion of institutional trust. Participants frequently referenced lack of NHS funding, its potential privatisation and expressed fears regarding the potential for corporate entities to exploit genomic datasets for profit-driven motives.

Representation and Visibility in Creative Educational Content

Across rooms, participants found the creative outputs culturally relevant and appreciated the diverse content that reflected their communities.

> *...loved it. I'm like, yes, I want to know more. I kind of found that it would be equivalent. I think it was really persuasive. Maybe the younger generation as well, to understand and get involved. it's quite engaging so yeah I found it interesting.*
>
> **#Room 1, Group no.2 , Invisible be visible, 7:28**

> *...another thing that I liked about the video was the fact that it showed a wide range of ages because at the beginning you saw you saw a young lady with her book like detailing her DNA structure but then you also see a shot of a older generation from like Asian Chinese I believe so that was quite good to see like it wasn't just focusing on like European it also focused on the far east ethnic minorities as well.*
>
> **#Room 3, Group no.2, DNA genomic video, 48:08**

> *I feel seen and I feel more recognised because, as I said in the previous group, growing up in my family, in my community, African Caribbean people, we always wanted to make sure we stayed healthy because we knew going to hospital is a risk.*
>
> **#Room 1, Group no.2, Video - Invisible be visible,10:53**

> *So I felt that was really good, sure, emphasising that this sort of study, not only is it important for the genome, but highlights the importance of personal touch, rather than just thinking as ethnic minorities...*

#Room 2, Group no.3, Video - World Health Organization, 04:26

While the four videos were acknowledged for their relevance, they were often described as being emotionally neutral, therefore reducing resonance with participants. As one participant noted regarding the value of Genomics studies:

> *The food we eat, the stress at home. So yes. And plus, we will remember a lot of our ancestors have gone through famine, through wars, and apparently we carry that DNA with us.*

#Room 1, Group no.1, Video - Invisible be visible,13:32

> *So, we're missing out. I think that video basically kind of tells you the benefits of why we should be participating in trials and supporting the healthcare system in trying to get more research in regards to conditions that are maybe hidden in our ethnic minorities.*

#Room 1, Group no. 1, Video - Invisible be visible ,12:22

> *So, there's been less participation from a group within the Muslim community.*
> *In terms of research, it doesn't go out into the communities. There's hard to reach communities that will never, ever know anything about this.*

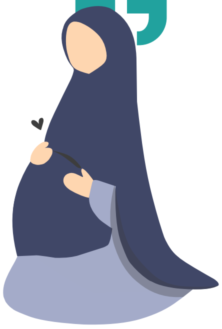
#Room 2, Group no. 2, Video - World Health Organization 05:15

> *And I think as well, we're more inquisitive. The older generation, they just accepted things as they were. They were talked about great if they weren't, you didn't question it. They have not come with the full knowledge of their family history and background.*

#Room 2, Group no. 3,
Video - World Health Organization, 13:44

Although each session produced wide ranging conversations, emerging patterns became noticeable when the discussion centred on particular areas of concern, such as risks around accessibility and exploitation of data etc.

> *My only concern was the data, if it continues to be taken on generation to generation, assuming that you give your data at birth, assuming that you've gone the wrong path, could you form it in the wrong hand where somebody can track you down who you are and things like that because of your data.*



#Room 4, Group no.3, Video - Are we looking into the abyss?, 7:22

This type of comment is indicative of a recurring concern continually juxtaposed with past historical abuses, such as eugenics and state sanctioned health interventions that were carried out without full transparency and consent of those who participated.

Evidence of the impact from creative outputs can be further witnessed from participant observations and ethical considerations, while evaluating potential harms and benefits, emphasising the importance of direct medical expertise and advice being more easily accessible:

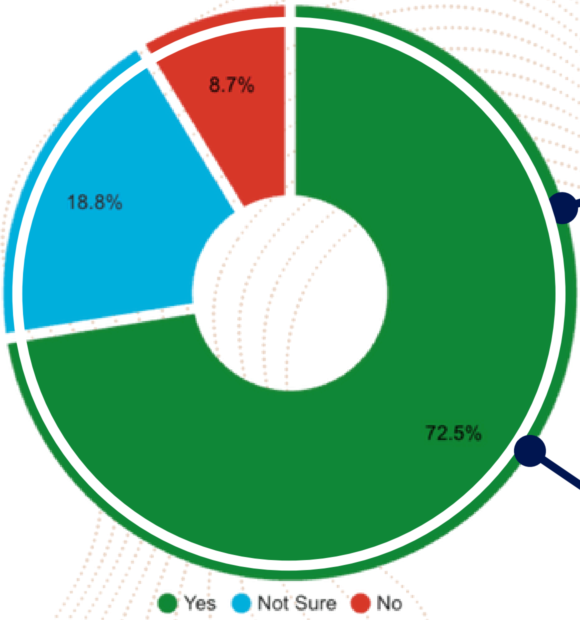
> *The positives are more than the negatives like you know getting a healthy child born without any symptoms and whatever it is it's a lot better than not knowing what your child's going to grow up with.*

#Room 4, Group no.4, Video - Are we looking into the abyss? 09:22

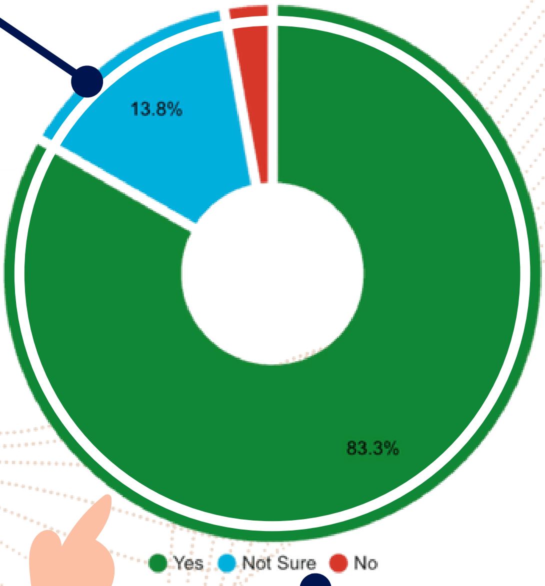
Correlations and Variances between Data Sources

Quantitative Data Analysis: Survey Results

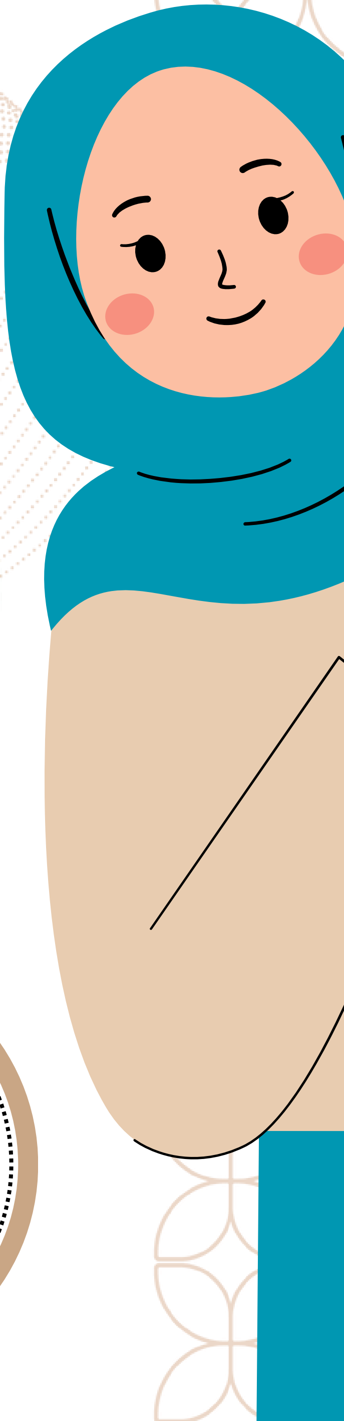
Quantitative data obtained from PAVE questionnaires illustrated participant confidence and positivity towards creative content/videos shared.

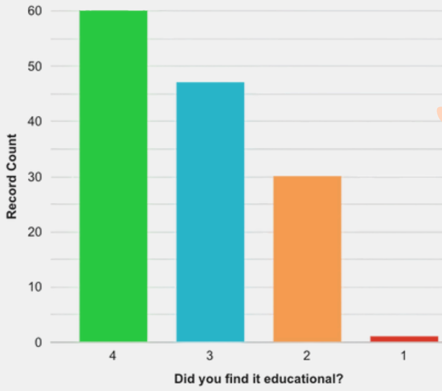


Did it help you to think about some of the ethical considerations surrounding genomics and the Generation Study?

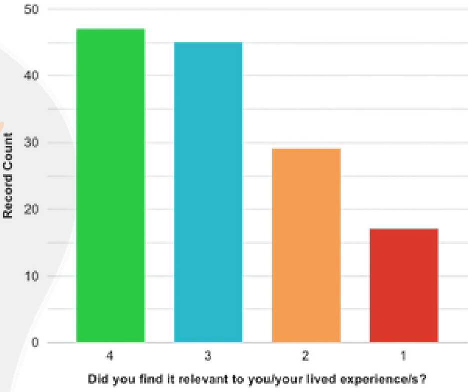


Did the video help you to understand more about the Generation Study/genomics and the role it plays/can play in society

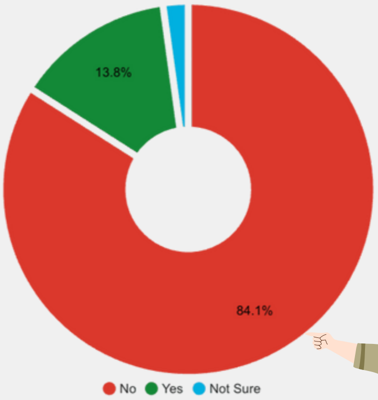




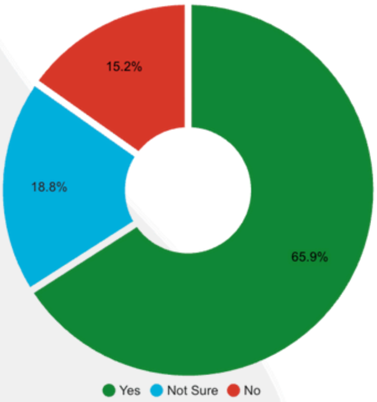
1 = Not at all 4 = Extremely



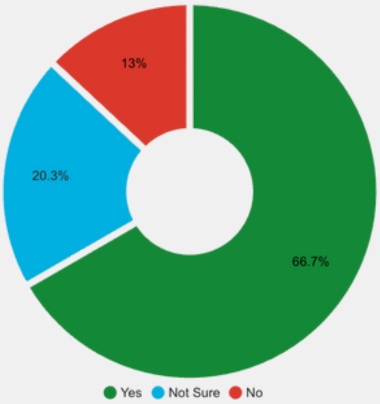
1 = Not at all 4 = Extremely



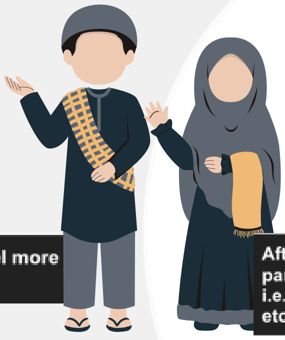
Did anything in the video make you feel uncomfortable?

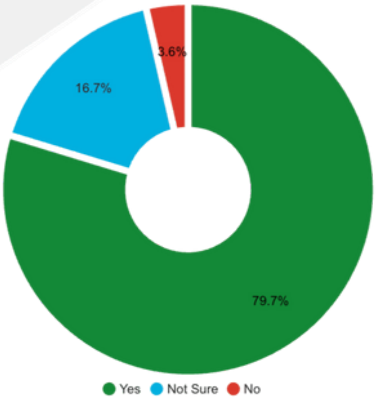


Have your views on the Generation Study / genomics changed after watching this video?



Was there anything in the video that made you feel more reassured or comfortable?





After watching this video, would you feel more comfortable taking part in Genomics or health research such as the Generation Study, i.e. more likely to take part in clinical trials or research or surveys etc.?

Quantitative Data Analysis: Survey Results

Although correlation between quantitative and qualitative results are evident, variances are identifiable among the latter data, obtained from group discourses where participants appeared to be more forthright and comfortable expressing caution towards genomics studies:

> *So I think this is a bit more inclusive. And I think because it also mentions, like this lady said, about the misconceptions that people might have, the concerns they might have about participating, because it gives those views and it kind of highlights the kind of concerns people in the community might have about participating and then it sort of dispels them.*

#Room 2, Group no.2,
Video - World Health Organization ,2:40

Other participants highlighted video representations excluded people with additional needs, such as those with audio/aural impairments:

> *...disability, it needs to be recognised, it needs to be shown. I understand there's hidden disabilities in the field, like autism is a disability that is very hidden.*

#Room 1, Group no. 1, Video - Invisible be visible, 07:48

Prominent Participant Concerns:

Genomic data misuse by third parties.

Absence of comprehensive and long-term framework that provides awareness and community consent/buy-in

Cultural and racial insensitivities around screening .

Risk of increasing healthcare stratification.

The aforementioned concerns should come as no surprise when considering community perspectives that are borne out of historical and more recent medical challenges regarding the lack of transparency surrounding healthcare practices.

Fears and scepticism continue to be a feature; however, these appear to be counterbalanced with a degree of cautious optimism when community awareness and engagement programmes are introduced, expanding avenues for exploration and dialogue around sensitive topics such as genomics.

Perceptions of Ethics & Malpractice

Building upon the themes discussed, it is critical to acknowledge how deeply perceptions of ethical risk and memories of historical malpractices are embedded in the collective psyche. For example, participants invoked not only recent data breaches, but also historical examples such as the more recent Windrush scandal (UK) and historic Tuskegee Syphilis Study (US), to name a few. These references were often coded in language such as "we've seen this before," or "they always test on us first." Such statements suggest a form of social memory that informs the current distrust in a manner not always fully captured by standardised surveys.

Some participants expressed concern over the potential for future genomic data to be weaponised in discriminatory immigration or employment policies linking historical patterns of racial profiling to fears of a digitised future.

> *I don't know how I feel about this whole situation and the vaccines, with everything that everybody went through, the whole world, close family, friends, people on social media.*

#Room 2, Group no.1,
Video - World Health Organization, 12:11

Additionally, discussions in Room 4 introduced the idea that ethical frameworks must extend beyond compliance and become dialogical. Several participants argued that the concept of 'informed consent' needs to be contextual, iterative, and intergenerational, especially when dealing with genomic information that could affect family lineage.

The ethical concerns expressed spanned:

Procedural (lack of transparency in data handling)

Relational (who gets to decide for whom?)

Existential (the future implications of being ‘known’ genomically before personality has formed)

These concerns suggest that ethical guidelines must account for not just biomedical principles, but also cultural, familial, and spiritual dimensions of health autonomy. This context demands that genomic initiatives like the Generation Study do more than disseminate information; they must actively acknowledge past harms, engage in culturally competent dialogue, and co-create consent and governance frameworks with the communities they aim to serve.

The concerns echoed during group discussions, underline the enduring need for transparency, accountability, and relational trust. Without these, even the most scientifically sound innovations risk alienation from those who need them most, and conversely, the absence of community voices equally impacts the effective development and progress of key sciences, like genomics. To summarise, the following themes can be identified from the participants in the different groups:

The importance of trust and need for transparency was observed via the inadvertent scepticism of some participants regarding the collection of data relating to ethnicity and how it was being used.

According to their perceptions, involving local community members in the consultation process, as well as providing feedback on any changes to ethnicity coding, would go some way towards mitigating these concerns.

Summary of Key Responses

Trust is relational, shaped by history and identity.

Participants desire clearer, culturally anchored communication.

Ethical concerns, especially around consent, remain under-addressed.

Increase need for understanding and working with cultural complexity.

What emerges from these sessions is a picture of tentative optimism - where many participants recognise the potential benefits of genomic screening, particularly for early intervention and long-term preventative care, they are equally concerned about ethical oversight, lack of reflective representation, and the potential mishandling of sensitive data. Crucially, this scepticism is not simply a reaction to the Generation Study in isolation, but rather, a response to the broader landscape of medical disservice and perceived state surveillance that have disproportionately affected Black and Asian Muslim communities.

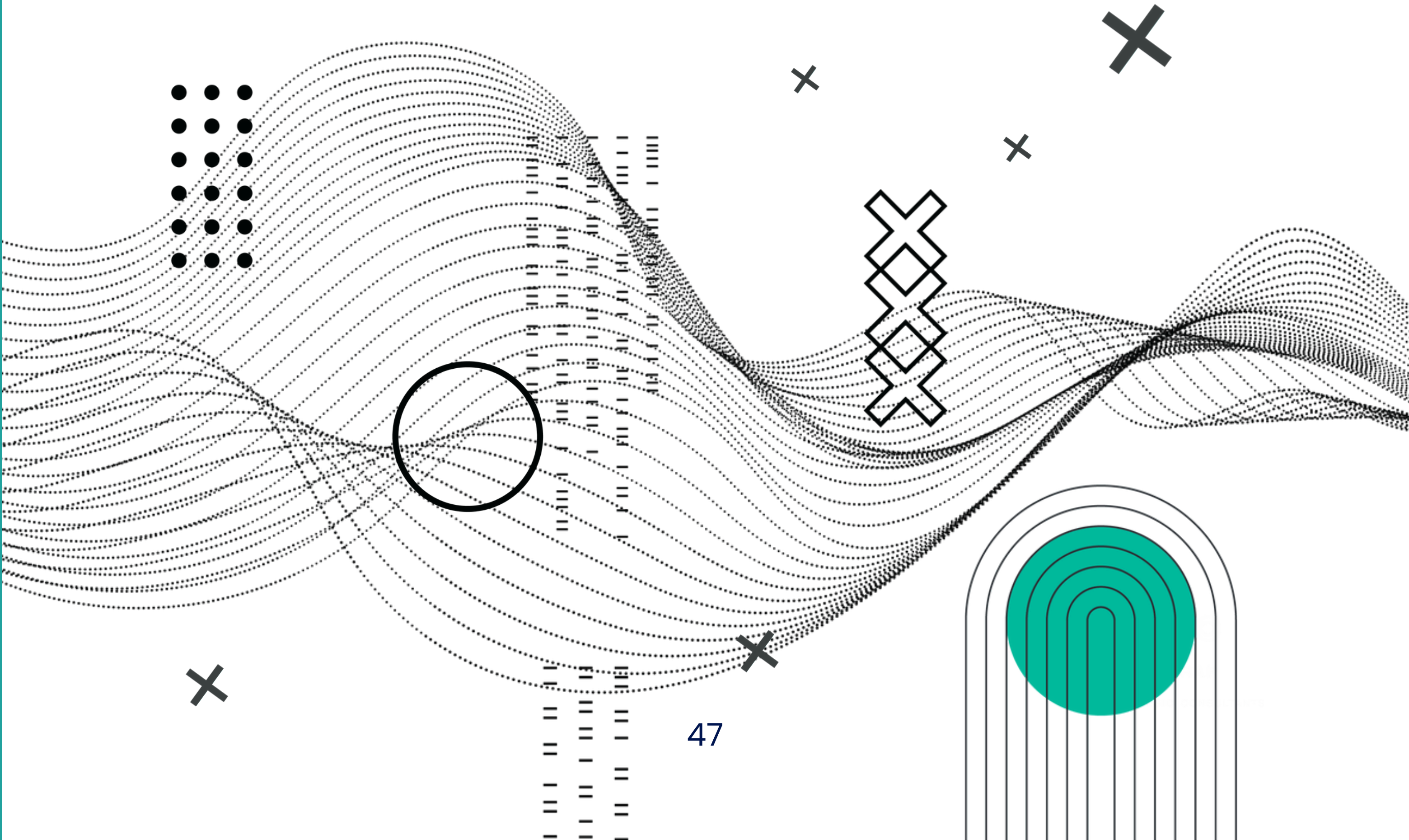
To address the issues highlighted here, the following steps need to be considered:

- **I. Meaningful action** should include community outreach and engagement with local communities to ensure any future changes to ethnicity categories is done collaboratively to accurately represent communities. Community participants suggested the more information people were provided with, the more willing they would be to share their details. This was teamed with the need to be held accountable.

- **ii. Clear explanation of the wider determinants of health** and how these relate to health outcomes, and the connection between ethnicity and health. This needs to be readily accessible for communities to understand using a variety of resources, such as easy reading material, visual aids, simple English and community languages.

- **iii. Create targeted interventions** to improve the knowledge pool of ethnicities among staff and patients. A range of strategies, including professional development/staff awareness and coaching programmes, should be used so they are conversant as to why data is being collected, how it is recorded and how it will be used in accordance with GDPR guidelines etc.

- **iv. Improve data sharing agreements**, particularly in light of some participants being unaware that their respective ethnicities can be connected to health conditions and outcomes.



Conclusion

Conclusion

This report has highlighted the layered complexity of community responses to the Generation Study and the broader implications of implementing genomic medicine in ethnically diverse and historically marginalised communities. Through a mixed-methods approach, integrating quantitative data with the rich qualitative narratives of participant group discussion, results have identified an overall enthusiasm among the groups for early diagnosis and innovation via genomics; however, this is tempered by enduring legacies of mistrust and existing structural inequality.

The exercise also highlighted the need to apply a community participatory approach to research, centring stakeholder voices while rebalancing institutional power relationships between researchers and their target audience, involving the latter within the decision-making process. This model of community-focused data gathering is rooted in the identified needs of communities and local organisations that represent the future of essential but inspired research for social change.

Community-focused research approaches are collaborative and co-produce knowledge with members of seldom heard (or deliberately silenced) communities, enabling disenfranchised peoples to author their own narratives instead of external actors speaking on their behalf. The insights together with foresights generated by this approach empowers such communities, equipping them with strategic capabilities to actively participate and contribute towards sociopolitical change. Capacity building then becomes an integral component within these communities, with a commitment to supporting learning and development underpinned by an intrinsic understanding of and sensitivity to cultural diversity. In practice this implies organisations and their staff (including volunteers) developing the relevant competencies while being sensitive to people’s cultural identity and heritage.

This Birmingham case study emphasises how trust is relational and built incrementally, not assumed through traditional and somewhat colonised institutional authority that amounts to community-targeting. Participants brought lived experiences into the analytical space, linking historical harms - such as unethical testing practices and failures in the Covid pandemic response - to current initiatives. These narratives reveal how public health is experienced, not just through clinical touchpoints, but through social memory, community values, and political histories.

In light of the above and, when comparing the methodological approaches used in this report with other research outcomes, such as The Muslim Census Online Survey, there appears to be a degree of congruence vis-à-vis quantitative responses insofar as participant optimism and support for further genomics research development. However, slight divergence from such overwhelming positivity emerges among PAVE qualitative findings when evaluating the more direct and interactive group sessions.

Participants elucidated more emphatically about their concerns, doubts and scepticism surrounding genomics studies during these sessions. A cautious optimism regarding the objectives of the study remained, however, this was coupled with concerns that continued to be pervasive across the research. Effective implementation of the Generation Study must therefore address three main imperatives:

First, it must embed culturally responsive frameworks that move beyond representation as tokenism toward genuine community-focused co-design. In other words, communities have to lead through empowerment and interactive awareness programmes where they are not confined to remote tick-box research that are extractive and unreflective of their lived realities or experiences.

Second, it must uphold transparency and reflexivity in consent, communication, and data governance, and third, it must position equity, not as a secondary factor, but as a foundational principle - ensuring that access, understanding and benefit-sharing are equitably distributed. Minority community participation in such health research is more likely if the medical and statutory agencies conducting the studies are familiar to them and they are approached as community partners as opposed to targeted recipients who are subjected to extractive research.

Ultimately, genomics holds a transformative potential; however, success depends on its ethical credibility. If communities are to participate with confidence, they must see their values, voices and safety reflected throughout the research process. By foregrounding these perspectives, the Generation Study can serve both as a scientific milestone and model for inclusive, socially accountable innovation.

Policy Recommendations:

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Policy Recommendations:

1. **Expand ethnic and cultural representation** in outreach materials to encourage increased acknowledgement and buy-in for engagement and interaction sessions such as PAVE or similar frameworks.

2. **Use community ambassadors** to act as conduits between healthcare institutions and communities, building localised and statutory trust between the involved parties.

3. **Maintain active consultation/feedback channels** so participant voices are visibly acted upon. Contrary to community-targeted research whose primary methodology is one where healthcare/academic or statutorily appointed entities parachute into communities to extract data, community-focused approaches ensure participant involvement during the research process, as well as notification and, where required, consultation and review of research outcomes.

4. **Support community-focused development** that also acknowledges members as stakeholders following engagement sessions like PAVE, empowering participants to become community researchers where they are equipped to continue raising awareness and identify new areas of significance that impact their respective communities in healthcare, thereby creating a platform for further research to address the subsequent challenges that have been identified.

Endnotes & Acknowledgements

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Endnotes:

[1] Bhui K, Warfa N, Edsell M. Islam, mental health and the London bombings: a cross-sectional study . BMC Psychiatry. 2009;9(1):50. https://doi.org/10.1186/1471-244X-9-50

[2] Lorimer R, Visser R. Media Representation of Muslims and Mental Health . In: Ventegodt S, Merrick J, eds. Islam and Mental Health . 2020.

[3] Lester H, Higton E. Delivering culturally sensitive mental health care for ethnic minority patients . Advances in Psychiatric Treatment. 2011;17(4):233–241. https://doi.org/10.1192/apt.bp.108.006641

[4] The Royal College of Obstetricians and Gynaecologists (RCOG). Ethnic Disparities in Maternal Outcomes in the UK: A Review . London: RCOG; 2020.

[5] Bewley S, Vigo D, Hezelgrave N. Reducing maternal deaths in the UK: lessons from confidential reports . BMJ. 2009;338:b1226. https://doi.org/10.1136/bmj.b1226

[6] Khan KS, Wojdyla D, Say L. WHO analysis of causes of maternal death: a systematic review . The Lancet. 2015;367(9516):1066–1074. https://doi.org/10.1016/S0140-6736(06)68399-3

[7] Goyder E, Blank L, Peters J, et al. Ethnic differences in HbA1c levels in individuals without known diabetes: cross-sectional analysis of the UK Biobank cohort . BMJ Open. 2017;7(2):e013862. https://doi.org/10.1136/bmjopen-2016-013862

[8] Forouhi NG, Misra A. Diabetes in South Asians: Unmet Needs and Research Priorities . BMJ. 2019;365:l1531. https://doi.org/10.1136/bmj.l1531

[9] Zeh J, Adekoya-Kole P, Sowden G. Understanding the barriers to diabetes self-management among Bangladeshi people in the UK . Primary Health Care Research & Development. 2012;13(2):145–154. https://doi.org/10.1017/S1463423611000426

[10] Sattar N, Gill JM. Ethnicity and its impact on cardiovascular disease and type 2 diabetes in the UK . JRSM Cardiovasc Dis. 2011;1(1). https://doi.org/10.1258/cvd.2011.000018

[11] Chaturvedi N. Cardiovascular disease in Britain's South Asian community . BMJ. 2001;322(7282):355–356. https://doi.org/10.1136/bmj.322.7282.355

[12] Bhopal R. Migration, ethnicity, race, and health in multicultural societies . Oxford University Press; 2014.

[13] Harding S, Bostock L, Blake M. Understanding Minority Ethnic Health Inequalities in the UK . York: Joseph Rowntree Foundation; 2012.

[14] Nazroo JY. The structuring of ethnic inequalities in health: explanatory frameworks and future research agendas . Sociological Research Online. 2003;8(1). https://doi.org/10.5153/sro.770

[15] Equality and Human Rights Commission (EHRC). Religion and Access to Health Care: The Experience of Muslim Patients in the UK. London: EHRC; 2010.

Acknowledgements

STRAP would like to thank its partners at Genomics England and the NHS Central and South Genomic Medicine Service Alliance, whose collaboration enabled this grassroots-led model of participatory engagement. The study would not have been possible without the trust, insight and generosity of the community organisations and participants who chose to participate in the PAVE sessions. We appreciate the contribution of each participant who shared their time, stories, concerns and aspirations. We would also like to extend thanks to the PAVE room facilitators, STRAP team members and community engagement officers who were involved in recruitment, visiting mosques, universities, community centres and faith-based institutions to ensure participants felt heard, informed and empowered before the event. Those behind the scenes who managed logistics, data entry, transcription and audiovisual documentation are also duly acknowledged. Acknowledgement is also extended to the authors of this report, its reviewers and broader STRAP consultancy network, whose academic rigour and expertise contributed towards shaping the dimensions of this project. Finally, this report is dedicated to the communities that participated and the forthcoming generations it has endeavoured to represent.

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Thankyou

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