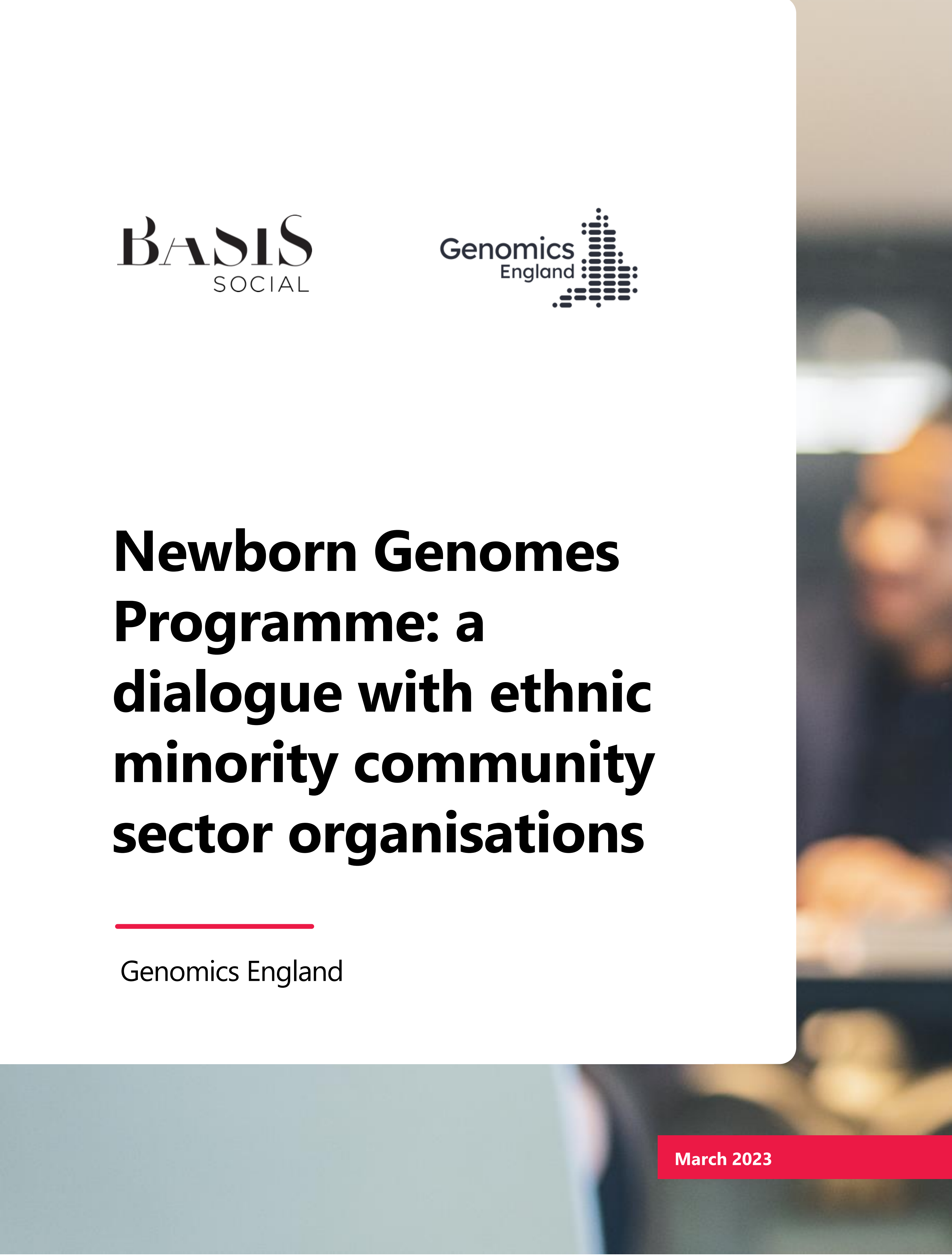

Newborn Genomes Programme: a dialogue with ethnic minority community sector organisations

Genomics England

March 2023

contents

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- African Voices Forum
- Asian Resource Centre of Croydon
- Croydon BME Forum
- Derby West Indian Community Association
- Derbyshire Gypsy Liaison Group
- Elays Network
- Eritrean Community In The UK (ECUK)
- Friend, Family and Travellers
- Friends of the Caribbean
- Hindu Forum of Britain
- Island House Community Centre
- Jalaram Sadavrat Trust Leicester UK
- Kiran Support Services
- Lincolnshire Traveller Initiative
- London Gypsies and Travellers
- Malayalee Association of the UK (MAUK)
- Mildmay Community Centre
- Nigerian Yorkshire Communities Network UK CIC
- Onevoice4travellers
- Osmani Trust
- Parentskills2go/ Distinct Family Services
- Sikh Community Centre Leicester
- South Asian Health Action
- The Return Project
- Tower Hamlets WorkPath

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1. Executive Summary

This report presents the findings of research commissioned by Genomics England in January 2023 and delivered by Basis Social between January and March 2023.

Genomics England commissioned this research to better understand how to design and communicate the Newborn Genomes Programme (NGP) research study in a way that is fair and inclusive, removing barriers to participation for expectant parents from five ethnic minority communities. The NGP study is an NHS-embedded research study to explore the benefits, challenges, and practicalities of sequencing and analysing newborns' genomes. Depending on its results, the NGP could pave the way for what would be the first national newborn screening programme in the world to incorporate whole genome sequencing.

Through engaging with representatives of 25 organisations, each of whom work directly with ethnic minority communities, this research provides a clear sense of the challenges and opportunities for Genomics England, with implications for communications and engagement approaches both in the pilot programme and any future roll-out of the NGP.

Stakeholders involved in this research demonstrated a strong interest in health research, in terms of the benefits it could afford those communities they worked with, and were therefore broadly supportive of the NGP and Genomics England's aims and ambitions for the programme. However, at a community level stakeholders highlighted a range of barriers that could impact the way in which the NGP might be received and limit uptake amongst expectant parents. These barriers ranged from a lack of knowledge and awareness – impacting the perceived value of participating - through to more fundamental issues relating to historical persecution, differences in social norms and belief systems which were seen as impacting trust in health research, and genetic research specifically. Understanding and addressing barriers will be key to engaging members of these ethnic communities in the NGP.

To build awareness of the NGP, and start to normalise conversations around health research, there is a need to communicate the aims and objectives of the programme. This will need to be done at a number of levels: firstly at a societal level to highlight that the NGP is aiming to be inclusive of everyone and to normalise health research; secondly at a community level, ensuring that different local and ethnic communities receive tailored engagement to address specific needs and concerns; and lastly with expectant parents directly.

At present the language used to introduce the NGP (and the all-in consent offer) is thought to be too complex and technical, and the nature of what people are being asked to commit to is too loosely defined as to address concerns that parents may have with participating. In particular, there are questions around how a baby's data may be used in future and what people would be committing to in terms of being recontacted for further research. Providing greater specificity here will be important, including what is known (and not known) around how data might be used and the support that will be provided to participating parents where genetic conditions are identified. Genomics England will need to communicate this information using simpler terms than are used presently, drawing on imagery, videos, testimonials and story-telling techniques. It is important that these are inclusive of the range of ethnic communities present in the UK, without being seen as targeting a specific community.

Engaging with communities through a top-down approach (i.e. as Genomics England or the NHS at an organisational level) is unlikely to be effective beyond those sections of communities who are already more aware of health research and open to participating in an initiative like the NGP.

To remove barriers to participation of expectant parents of those ethnic minority communities that were the focus of this research there is a need for Genomics England to work closely with individuals and organisations that have the credibility to communicate messages around the NGP. This is most likely to involve a combination of:

- those VCSOs that work within communities delivering support on related issues (notably health and wellbeing) who can co-produce a plan for engaging communities at a local level, with VCSOs helping provide a ‘bridge’ for Genomics England to engage with their communities;
- local healthcare practitioners (e.g. GPs, midwives) who can answer questions in more of a one-to-one setting with expectant parents; and
- community ‘champions’ who are members of the public whose role would be to raise awareness through reaching out to those groups that are less engaged with formal services.

A bespoke engagement approach is likely to be needed within each of the pilot areas to map relevant communities and services, and to co-produce an engagement approach, with appropriate resource allocated to ensure that VCSOs can commit staff time to supporting Genomics England. While there is good will from those organisations involved in this research, there are also still a large number of questions around the NGP that VCSOs would need answering before feeling able to support Genomics England.

This research provides Genomics England with a range of general and community-specific insights that can help shape the way in which the NGP is positioned and how communities are engaged in support of the pilot programme and any subsequent roll-out. It has highlighted the importance (and challenges) in building trust, and some of the ways in which this may be achieved. It will be important to continue fostering and expanding these relationships with VCSOs, and to begin engaging in direct dialogue with members of different ethnic minority communities themselves, albeit as one equal part of their local community.

2. Background, objectives and research approach

2.1. Background

Genomics England's Newborn Genomes Programme (NGP) is designing an NHS-embedded research study to explore the benefits, challenges, and practicalities of sequencing and analysing newborns' genomes. Depending on its results, the NGP could pave the way for what would be the first national newborn screening programme in the world to incorporate whole genome sequencing.

As a research study, the NGP requires research ethics approval before proceeding. A research ethics committee will examine the study's research protocol and decide whether to approve it.. Key to this protocol, and any future delivery of the study thereafter, will be a rigorous account of how the NGP proposes to approach the question of participant consent.

For the NGP, consent will be sought from newborns' parents. In order to participate, parents will need to agree to all three parts of the research study. Genomics England call this consent model an 'all in' approach. The three parts of the study that parents will need to agree to are:

- letting Genomics England store the genome and automatically receive data about their newborn's health. The data will be used to evaluate the screening panel, as well as by health researchers looking to advance understanding of genes and health more broadly; and
- having their newborn's genome sequenced and receive results from the screening panel;
- allowing Genomics England to contact them in the future about opportunities for qualitative or quantitative research, and other health research offers.

The complexity of parental consent on behalf of their newborns was recognised by participants in Genomics England's July 2021 public dialogue on whole genome sequencing. They emphasised the need for further detailed consideration, public dialogue, and research to examine the practicalities and ethical issues associated with consent before, during, and after its research study. The participation of individuals from a diverse range of backgrounds in the NGP's work was also a recommendation from dialogue participants, and from key stakeholders whom it has collaborated with subsequently.

Testing the feasibility of whole genome sequencing means ensuring that the NGP research study reaches a diverse range of communities equitably to offer participation in the study. This, in turn, means the NGP needs to involve as wide a range of parents and babies as possible, to understand how the consent model could work nationally; and to evaluate rigorously the benefits and impacts of the NGP consent model on participation.

To help achieve this, in January 2023, Genomics England commissioned Basis Social to conduct a programme of qualitative research with representatives of voluntary and community sector organisations (VCSOs) working closely with people from a range of ethnic backgrounds. This report presents the findings of this research.

2.2. Objectives

The objectives of this research was to develop a more comprehensive view of:

- the attitudes of people from ethnic backgrounds that are typically underrepresented in health research to the NGP's consent model and offer to parents;
- the potential barriers that VCSO representatives see to people from different ethnic backgrounds participating; and
- how key messages and processes can best be shaped to address these barriers.

2.3. Research approach

To achieve these objectives, Basis Social developed and implemented a programme of research that was designed in response to the following four challenges:

- First, the UK is home to a diverse range of ethnic groups, and it would not be possible within the timeframe or the resources available to engage with all of them. Therefore, the study demanded a clear rationale for the selection of which ethnic groups would form the main focus of the research.
- Second, ethnic groups are themselves extremely internally diverse. This is because group members' attitudes, barriers and receptivity to messaging will be shaped not just by their ethnicity, but by factors including religion, nationality, cultural background, upbringing, time spent in the UK, and where they live. For the study findings to be robust and actionable by Genomics England, it was important to try and capture the heterogeneity of views present for each ethnic group.
- Third, and relatedly, there is a risk that the study's findings will not be considered credible by people from the ethnic backgrounds themselves, unless the sample of VCSOs included in the research reflects the diversity of the people they work with.
- Fourth, and finally, the study had to be delivered within a short time frame, between January and March 2023, for the findings to be useful for the research ethics committee submission, and the expected delivery of the study thereafter.

The following sections provide further details about the research approach, including:

- which ethnic groups formed the focus of the research, and why;
- the research design;
- the sample of VCSOs who participated in the research;
- the materials used during the research;, and
- the strengths and limitations of the study.

Selection of ethnicities to focus on

This research involved research with VCSOs working with people in the UK with the following ethnic backgrounds:

- Black African

- Black Caribbean
- Indian
- Pakistani
- Gypsy, Roma and Traveller

These ethnicities were selected because they cover:

- the four key populations of interest outlined in Genomics England's Diverse Data Strategy (p11);
- representation of a range of major religions in the UK (an important intersectional factor)
- a diversity of genetic health issues and conditions
- communities with which Genomics England has had little direct experience engaging with in the past – most notably, Gypsy, Roma and Traveller communities

Research design and analysis

The research design consisted of three distinct phases – **Scoping**, **Listening**, and **Ideation** – which are described below.

Scoping Phase

During the scoping phase, Basis Social conducted a mapping of VCSOs working closely with people from the five ethnic backgrounds of interest living in England. The purpose of the mapping was to build a database of potential organisations who could be engaged in the research. The database included the organisation's name, contact details, and notes on geographic, thematic and demographic focuses. The database only included information that was available in the public domain, for example via search engine queries and the review of organisational websites.

Listening Phase – Methods

The objective of the Listening Phase was to understand the attitudes and potential barriers to engaging each ethnic group in the NGP. This was achieved via three workstreams.

- First, a rapid desk review of existing evidence and literature was conducted. This was to ensure the materials used in subsequent workstreams and research phases were informed by existing knowledge and did not seek to reinvent the wheel.
- Second, all organisations included in the scoping database for whom email addresses were identified were sent a short online survey designed to capture relevant attitudes and perspectives towards the NGP. The main objective of the survey was to provide as many organisations as possible with an opportunity to share their views as part of the research. The survey was designed and delivered via SurveyMonkey, and took approximately 10 minutes to complete. The survey was not incentivised. Two reminders were sent to organisations that did not complete the survey after the initial invite. Of 168 organisations who received the survey, 8 completed the survey. These low response rates were not unexpected. As the scoping database was developed

using information available in the public domain, many of the email addresses used were generic organizational email addresses (e.g. info@...) rather than personal addresses. Moreover, VCSOs must often juggle competing responsibilities, limiting their opportunities to complete online surveys, particularly those that are unable to compensate them for their time.

- Third, 25 interviews were conducted with representatives of 25 VCSOs (5 per ethnic group). Interviewees were matched with moderators of a similar ethnic background. These interviews were conducted online and lasted for one hour, using a semi-structured topic guide. As part of these interviews, two videos were played to participants, one providing information about the NGP as a whole (the 'Baby Ali' video, which will be shown to parents who will be asked to consent to their babies' participation in the study), and the second providing more specific detail about the all-in consent model (see below for more information). With the interviewee's consent, these interviews were recorded for analysis purposes. Interviewees also received a £50 donation (for their VCSO or a related cause) to cover their time and to thank them for their input. For further information about the selection and recruitment process for these interviews see the next sub-section ('Sampling and recruitment').

Listening Phase – Stimulus

The two videos used as stimulus for the Listening Phase interviews are described below.

Video 1: The 'Baby Ali' Video

The 'Baby Ali' video is a short, 5 minutes animated video designed by Genomics England for parents of potential participants in its research study. The design and content of the video was informed by user research and testing, plus benefited from professional graphic design and copywriting. The video provides information about the key aspects of the NGP, including the objectives of the study, how samples will be taken, how the data will be used, and by whom. The video also calls out and seeks to allay specific concerns with parents may have - for example, their child being used as a "guinea pig".

Video 2: The All-in Consent Offer Video

The All-in Consent Offer is a 10-minute video that was created bespoke for this study, and that was produced within a short timeframe. The video is a recording of a member of Genomics England presenting a series of slides to explain:

- what consent means in the context of health research
- what the five parts of the NGP all-in consent offer are, and what they mean in practice

Ideation Phase

The ideation phase consisted of a 2-hour workshop with the each of the five sets of VCSO representatives who participated in the interviews (5 workshops total). The purpose of these workshops was to report back to participants the findings from the Listening Phase, and to gather their input on ways to enable people from the five ethnic backgrounds to participate in the NGP, should they wish to. As with the interviews, these workshops were conducted online and used a semi-structured topic guide. For continuity purposes, each workshop was moderated by the same person who had interviewed the participants during the Listening Phase. All participants in the workshops received a further £100 donation to cover their time and thank them for their contribution.

Analysis

Each interview and workshop was moderated by a researcher from Basis Social and the audio, video, and chats were recorded. Permission to record the sessions was requested in the consent form sent to participants at the moment of recruitment, as well as verbally at the beginning of each interview and workshop. Selected members of Genomics England staff were also able to view the workshops live as silent observers.

At the end of Listening Phase, an analysis session was held between Basis Social and members of Genomics England. This session helped inform the design of the workshop guide used in the Ideation Phase.

At the end of both the Listening and the Ideation Phase, the researchers completed an analysis 'pro-forma' for each of the ethnic groups interviewed. This was a document developed by the project lead following each phase to capture and compare findings, insights and observations from across the interviews and workshops and to identify key emerging themes. These themes, in turn, informed the development of the code-frame used to systematically code and analyse the data gathered during each interview and workshop. This coding process was performed using computer-assisted qualitative data analysis software to assist with transcription analysis, coding and text interpretation.

An initial report skeleton was developed to allow Genomics England to review and provide feedback. The full report was then written using the outline as a guide with continuous reference back to the findings and quotes.

Sampling and recruitment

Recruitment for the interviews and workshops employed a two-pronged approach.

First, Basis Social and Genomics England worked together to create an invitation shortlist based on organisation captured in a scoping database. Shortlisted organisations were contacted directly by Basis Social and provided with information about the project, prospective dates for the interviews and workshops, and an invitation to participate.

Second, Basis Social worked in partnership with Ethnic Opinions, specialist recruitment agency, to purposively identify and recruit organisations not previously captured in the scoping database. These organisations were identified using a snowball approach that began with VCSOs that Ethnic Opinions already had strong relationships with, to identify suitable organisations.

Black African	Black Caribbean	Indian	Pakistani	GRT
Parentskills2go/ Distinct Family Services	Friends of the Caribbean	Hindu Forum of Britain	Tower Hamlets WorkPath	Derbyshire Gypsy Liaison Group
African Voices Forum	Derby West Indian Community Association	Jalaram Sadavrat Trust Leicester UK	Island House Community Centre	One Voice 4 Travellers

Nigerian Yorkshire Communities Network UK CIC	The Return Project	Sikh Community Centre Leicester	Osmani Trust	Lincolnshire Traveller Initiative
Eritrean Community In The UK (ECUK)	Mildmay Community Centre	Malayalee Association of the UK (MAUK)	Asian Resource Centre of Croydon	Friends, Families and Travellers
Elays Network	Croydon BME Forum	South Asian Health Action	Kiran Support Services	Roma Support Group

provides an overview of the final sample of organisations that participated in the research. The final sample was curated to ensure a mix in terms of:

- Audience focus (e.g. women, parents, specific nationalities)
- Thematic focus (e.g. employment, health, community advocacy)
- Geographic location

During the Listening Phase, each organisation was represented by one interviewee. There was minimal attrition between the interviews and workshop. Interviewees from two organisations in the Indian cohort did not attend the workshop due to technical difficulties joining the Zoom call. The original interviewees from two of the GRT organisations were unable to join the workshop but were instead represented by other members of their organisations.

Table 1: Participating Organisations

Black African	Black Caribbean	Indian	Pakistani	GRT
Parentskills2go/ Distinct Family Services	Friends of the Caribbean	Hindu Forum of Britain	Tower Hamlets WorkPath	Derbyshire Gypsy Liaison Group
African Voices Forum	Derby West Indian Community Association	Jalaram Sadavrat Trust Leicester UK	Island House Community Centre	One Voice 4 Travellers
Nigerian Yorkshire Communities Network UK CIC	The Return Project	Sikh Community Centre Leicester	Osmani Trust	Lincolnshire Traveller Initiative
Eritrean Community In The UK (ECUK)	Mildmay Community Centre	Malayalee Association of the UK (MAUK)	Asian Resource Centre of Croydon	Friends, Families and Travellers

Elays Network	Croydon BME Forum	South Asian Health Action	Kiran Support Services	Roma Support Group

Strengths and limitations of the study

Overall approach

Qualitative research offers depth of insight and is fully appropriate for complex subject matter such as new techniques and approaches in medicine and health research. The specific design of this research also drew on two distinct types of research approach. First, through the sequencing of the interviews and workshops, the study employed a deliberative approach, in which participants are gradually exposed to new information and perspectives over time, with opportunities to pause and reflect. Second, by giving VCSOs the space to ideate ways of enabling members of their communities to make informed decisions about participating in the NGP, the research employed a participatory approach. By blending these two approaches, the study aimed to empower participants to influence the development of future engagement activities that will be directed towards members of the communities they work with. It is unlikely that traditional qualitative approaches such as focus groups or quantitative surveys would have been fit for such a purpose. The level of nuance achieved through this qualitative design would also be hard to achieve via alternative methods.

While a qualitative approach was appropriate given the complex, exploratory and participatory focus of the research, it is not possible to generalise from the findings in the same way that would be possible if the research adopted a more quantitative approach. This research had a small initial sample size of 25 participants taking part in interviews and a closing sample (following dropouts) of 23. While these sample sizes are suitable for this form of qualitative research, they mean that the findings cannot be treated as representative of any particular group.

Sampling and recruitment

To be eligible for the study, it was decided that participants had to commit to both a 1-hour interview and the workshop from the outset. While participants were afforded flexibility in choosing the date and time of their interview, the workshop date and time was fixed to avoid logistical challenges in trying to agree a date and time that would work for all parties after they had been recruited. This requirement meant that some potential participants who wanted to participate were unable to do so, because of scheduling clashes.

This research used a qualitative approach, with project constraints and an online approach necessitating that group discussions were limited to no more than five individuals. Given the small sample size, it was necessary to adopt a purposive approach to sampling. While organisations were selected from a more extensive mapping exercise, the small numbers necessarily meant that we were not able to get representation from organisations accounting for factors such as size, location and nature of services provided. However, we did aim to recruit for variance in relevant sub-groups worked with (e.g. accounting for nationality and religious differences), and all organisations provide direct support to the relevant ethnic communities who might be involved in this research.

It is important to note that the organisations involved in this research often worked across different ethnic communities within a given locality, and could specialise in certain forms of support (e.g. health and wellbeing) or in working with specific sub-groups (e.g. women, or survivors of domestic abuse). While discussions focused on specific ethnic communities, it is possible that these other characteristics may have influenced the perspective of contributors.

Finally, the research focussed on five ethnic minority groups only. The results of this research are not generalisable to other ethnic minority groups, such as people of Bangladeshi descent. Further research may be needed in order for Genomics England to engage other such communities effectively.

Use of online methods

The online approach of the study enabled the research team to reach a wide representation of organisations working in communities across England. This would have been less feasible with a face-to-face approach. An online approach was also more convenient for participants to attend as there was no need to consider time to travel. This made it easier for individuals to fit the workshops around work schedules and other commitments. However, an online approach does mean that the research could not include participants considered to be digitally excluded. There were also some participants whose internet connections were weak and disrupted their ability to contribute to discussions fully.

An iterative approach to the research was adopted, to ensure that the topics for discussion during the Ideation Phase were aligned with participant priorities and interests, while still accounting for the overall objectives. The benefit of this was that the materials developed and areas for discussion were tailored to the needs of participants and helped to steer the dialogue naturally. There are, however, limitations to an iterative approach, namely it makes it more difficult to replicate the research.

Responses to the online survey were low. Consequently, **it will be important for future research conducted by Genomics England to seek to engage a broader and more diverse set of voices. We anticipate that this will be best achieved through more of a one-to-one approach**.

Stimuli

One of the core challenges of this research was the need to rapidly educate participants about the NGP, so that they could provide informed perspectives on potential barriers and enablers to participation by members of the communities they support. To achieve this, two videos were played during the Listening Phase interviews, one explaining the NGP generally (hereafter: the ‘Baby Ali’ video) and the other explaining the consent model (hereafter: ‘the consent video’). These videos served a triple purpose in the interviews:

- first, as educational material for informing participants about the NGP and consent model
- second, as stimuli for generating feedback on the content of the NGP and consent model
- third, as stimuli for generating feedback on the design of videos themselves, from a communications perspective

These videos provided an efficient method for simultaneously educating and generating feedback from participants. However, their limitations must also be noted.

The first limitation concerned differences in the quality of the two videos. The ‘Baby Ali’ video was a short (5 minutes) animated video designed by Genomics England for parents of potential participants in its research study. The design and content of the video was informed by user research and testing, plus benefited from professional graphic design and copywriting. These factors helped make the video accessible and engaging to participants.

The consent video, by contrast, was produced specifically for this study, within a short timeframe, and without the benefit of extensive user research or testing. It was also longer (approximately 10 minutes) and contained more complex information communicated in more technical language. As a result, there were elements of the consent model video that some participants found difficult to understand. Moreover, it was clear that some participants struggled to separate the message from the medium, leading them to focus more on the way in which the video communicated the information, rather than the actual content of what was being communicated. While such feedback is still useful from a communications perspective, this may have limited the ability of some participants to fully engage with the contents of the consent model.

A second limitation concerned the amount of time dedicated to watching videos as part of the interview. In the context of a 60 minute interview, 15 minutes of video is a long time, limiting the amount of time for discussion. For the longer, 10 minute consent model video, in particular, there was also a risk that participants would forget information provided at the beginning of the video by the end. To mitigate these issues, a more dynamic, phenomenological approach was taken to gathering feedback on the consent model video. While watching the video, participants were asked to raise their hand at any point at which either they personally had a question or concern, or they felt that parents would have a question or concern. Interviewers also studied their reactions while watching, pausing the video if the participants' facial expression indicated confusion or concern. This approach allowed the interviewer to hone in specifically on those parts of the video which warranted most attention, and also ensured that the conversation was not paused for excessive periods of time.

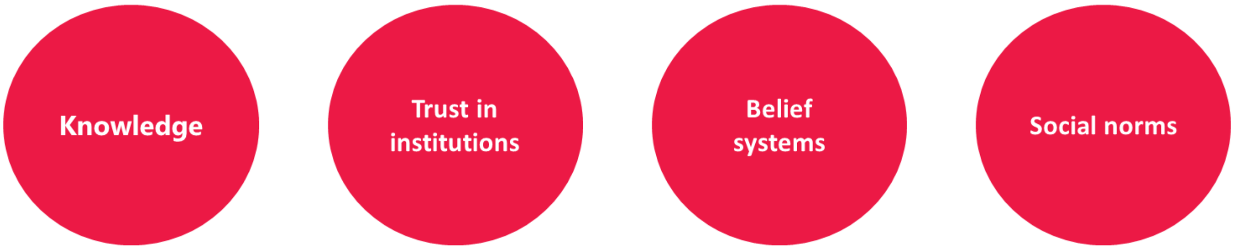
3. Contextual factors to be aware of when designing engagement approaches for different ethnicities

This chapters provides an overview of the key contextual factors that can help to anticipate and understand how people from different ethnicities may respond to the NGP.

It does this by drawing out the key themes underlying participants' explanations of why parents from the communities they work with may or may not be willing to participate in the NGP.

These themes fell into four categories, summarised in Figure 1 below.

Figure 1: Contextual factors to be aware of when designing engagement approaches



In the sections below, key contextual factors for the various ethnicities are summarised, together with key within-group differences. These factors are also referred to in subsequent chapters in the report, to help explain the findings.

3.1. Black African and Black Caribbean

Research with organisations working with Black African and Black Caribbean communities produced many overlapping findings between the two ethnic groups, but also some key differences. This sub-section provides an overview of the key themes that cut across both groups as well as the differences within and between those groups

Knowledge

As was true for all five ethnic groups, barriers to understanding the NGP were commonly reported. Participants were concerned that factors such as low prior awareness and knowledge of genetics, relatively low education levels, and the high volume of technical information associated with the NGP would make it difficult for parents and the wider community to understand the study, and to give truly informed consent.

Trust in institutions

Both Black African and Black Caribbean participants highlighted distrust in healthcare and health research as considerable barriers to participation in the study. While such distrust was also reported for other ethnic groups (notably GRT), the research highlighted a wide variety of ethnicity-specific drivers of this distrust among Black communities. These included:

- A common store of cultural memories of mistreatment and abuse of Black participants in health research – e.g. the Tuskegee syphilis trials

- Awareness of healthcare disparities (as well as wider social inequalities) that negatively affect Black communities
- Perceptions of the research and healthcare professions as majority white
- The legacy of COVID-19, including its influence over attitudes towards healthcare information and trust in healthcare institutions

Considering this distrust, **both Black Caribbean and Black African participants highlighted the importance of communicating the benefits of participating in the study, with a particular emphasis on the benefits *to Black parents and Black communities, specifically***. This focus on benefits to the community may be related to the view that Black communities have historically been exploited and taken advantage of for others' benefits.

Participants also highlighted the need for **robust contingency plans and an independent risk assessment as measures for demonstrating the trustworthiness of the study**. Partnering with credible role models – in particular, organisations working with Black communities and Black healthcare professionals and scientists – was also viewed as vital for demonstrating trustworthiness.

Belief systems

Participants noted that many Black African and Black Caribbean people are religious. However, compared with other ethnicities, religious beliefs were not a dominant theme.

Alongside religious beliefs, participants also highlighted the currency traditional healthcare practices, such as natural remedies, among Black African and Black Caribbean communities. These practices may carry strong symbolic significance due to perceived associations with Black and ancestral identities. Participants noted that they may also come into tension with modern medicine, with practitioners viewing more natural/traditional healthcare practices as more effective.

Social norms

Conversations about Black African and Black Caribbean highlighted two types of social norms:

- internal group norms – that is, norms about how members of Black communities behave within those communities
- external group norms – that is, norms around how members of Black communities behave in interactions outside those communities

The main internal group norm mentioned by participants was focussed on talking about health. Participants felt that this is uncommon in both Black African and Black Caribbean communities, particularly among men, but also among women.

In terms of external group norms, **participants reported a tendency among Black patients to pay lip service to what they think white healthcare professionals want to hear, as well as a potential risk of Black parents feeling pressured by white healthcare professionals to participate in the study**. This norm was attributed both to consciousness of racial differences and an authority bias.

Within-group differences

Many of the views expressed by organisations working with Black African and Black Caribbean were similar because of their shared Black identity as Black communities. Despite this point of commonality, however, there is a lot of diversity both within and across Black African and Black Caribbean ethnic groups.

At the broad, regional level, participants indicated that there are significant differences between the British-Caribbean and British-African experience. These differences may owe, in part, to differences in the history of migration between the UK and the Caribbean, on the one hand, and the UK and the African continent, on the other (e.g. the Windrush Generation).

At a national level, both the Caribbean and the African continent are home to many different countries, many of which are culturally and linguistically distinct from one another, as well as internally very diverse in terms of culture, language and religion. In addition, immigration from different parts of the Caribbean and Africa to the UK has resulted in a diverse array of hybrid cultural identities. All of this means that the experience of a British-Nigerian cannot be assumed as reflecting that of a British-Eritrean, or a British-Somali.

3.2. Indian

Knowledge

As was true for all five ethnic groups, barriers to understanding the NGP were commonly reported. These included low knowledge and understanding of the terminology / language around genetics and genomics medicine.

However, **research with organisations working with Indian communities suggested that the more fundamental challenge was around *awareness of health research itself***. This is because, in contrast with other groups (notably Black Caribbean, Black African and GRT), health research was not considered to be on the radar of people from Indian backgrounds. This was attributed to a lack of exposure to health research - **generally, it was felt that Indian communities were not typically involved in studies, and so community awareness of health research may be low compared to other groups**.

This stands in marked contrasts to Black and GRT ethnic groups, in particular, whose exposure to health research, particularly in the past, has often been extremely negative.

Trust in institutions

In contrast to all other groups, research with organisations working with Indian communities indicated that many in these communities trust healthcare professionals. This trust relates to several factors, including:

- The cultural cache of healthcare as a profession
- The number of healthcare professionals working in the UK who are of Indian descent

However, there was some evidence of distrust in the pharmaceutical industry, specifically. Important differences were also indicated between people of Indian descent who were either UK-born or who migrated from overseas from urban areas, and migrants from poorer and more rural parts of India (see below).

Within-group differences

Whether or not a person was born in the UK was commonly viewed as the major determinant of Indian people’s likely attitudes to the NGP. Those born in the UK were generally described as:

- A professional, educated, open minded community

- Often part of the health service as doctors/ specialists
- Trusting in the health service generally
- More used to having their opinions asked
- Feeling part of mainstream society, through strong integration
- More likely to understand the health system, as well as the benefits of health research
- More likely to be somewhat familiar with general concept of genetics/ genes
- Less reliant on family advice and less bound by cultural factors

Considering more recent migrants from India, participants drew distinctions based on whether they had migrated from an urban or rural area. Those migrating from a rural area were described as:

- Distrusting of healthcare – because of experiences of corruption within the Indian healthcare system
- Lacking knowledge of the UK health system
- Having priorities other than participating in health research – such as maintaining an income and supporting family
- Likely to have lower levels of English proficiency, and lower levels of education more generally
- Less likely to be familiar with/ able to grasp issues around genetics/ genome sequencing, the complexity around consent
- Very low awareness and understanding of what health research is
- Likely to worry about shame associated with giving birth to a baby with a genetic condition – especially if it is a girl
- Mistrusting of data collectors – particularly those collecting personal or sensitive data
- Fearful that their community is being targeted because of their ethnic background

By contrast, those migrating from an urban area were described as:

- More likely to have high levels of education and a professional background in high skilled industries, such as IT and healthcare
- Likely to understand the importance of health research and be open minded to engagement if they understand the benefits

3.3. Pakistani

Knowledge

Participants thought it likely that there will be little familiarity or understanding about genetics/ genome medicine across the board. Where differences were suggested, these focused on generational and educational issues:

- Younger, UK born and brought up – more versed in health/ medical terms, more open to concepts
- Older generations (who might be key influencers) and those more recently arrived

Trust in institutions

Unlike research with organisations working with Indian communities, discussions with organisations engaged with Pakistani communities highlighted that trust in healthcare is low and may be a barrier to participation. Participants indicated that such low levels of trust stem from a variety of factors, including:

- The impact of COVID in making Pakistani communities more aware of health disparities in the UK
- Experiences of unfair / discriminatory treatment within the NHS, especially secondary care
- For more recently-arrived migrants from Pakistan, the legacy of distrust in Pakistani healthcare, due to perceptions/experiences of corruption

Belief systems

Faith plays a key part in the lives of many people of Pakistani origins. The centrality of faith has implications for the NGP.

For example, with respect to genetic conditions, **one prevailing traditional attitude highlighted by participants is that such conditions are God's will and, as such, shouldn't be subject to any interference by medicine or parents**. Another interpretation which the NGP could encounter is that such conditions are God's punishment for parental/familial wrongdoing.

Owing to the centrality of faith in the lives of many people of Pakistani descent, participants said such attitudes would need to be addressed by religious leaders upfront and explicitly.

Social norms

Participants suggested that parents of Pakistani descent could be afraid to learn that their baby has a genetic condition – and even more afraid that others in their community might find out.

This fear was linked in part to religious beliefs regarding the causes of genetic conditions (e.g. punishment for wrongdoing).

However, this fear also linked to concerns about the marriage prospects of a child with a genetic condition (a particular concern for female children), as well as the stigma already attached within Pakistani communities to issues such as mental health and disability

Within-group differences

Similarly to participants' views with respect to Indian communities, whether or not a person was born in the UK was commonly viewed as a major determinant of likely attitudes to the NGP among Pakistani communities.

Those born/well established in the UK were generally described as:

- More engaged with health messages, and issues affecting the South Asian community
- More engaged in general with society at large, including institutions

- More likely to be fluent in English – although comprehension might vary depending on education levels
- Understanding on genetics/ DNA/ genome medicine may not very low – not an area they have cause to access

By contrast, more recent migrants were described as:

- Likely to have little knowledge of the UK health system
- Having little time for non-essential activities
- Having lower levels of English proficiency – need for translated materials, advice in mother tongue languages
- Having lower levels of education – might hinder understanding of complex concepts
- Less likely to be familiar with/ able to grasp issues around genetics/ genome sequencing, and complexities around consent
- Having low awareness and understanding of what health research is
- More likely to live in traditional households, characteristics of which include of extended family living, respect for elders, and patriarchal hierarchies

3.4. Gypsy, Roma and Traveller

Knowledge

The Gypsy, Roma and Traveller communities are three distinct ethnic groups that share many common characteristics. Consequently, this sections provides findings for GRT communities as a whole, as well as findings for individual groups.

GRT children rarely go to school beyond primary school. Some organisations provide an education bus that travels to site to encourage education beyond this. As a result, literacy levels are particularly low in the GRT community. The typical reading age of adults is age 9. Therefore, **when communicating with the GRT community, written materials should be avoided, and the focus should be on upskilling and informing key workers, and providing simple video materials which can be explained and shared**.

Trust in institutions

GRT communities often maintain deep-rooted suspicion of people and services outside their direct experience. Participants indicated that this is borne out of systemic misunderstanding and prejudice.

This distrust is manifested in the rejection of services or people who are not proven to be supportive and empathetic. **Services that are acceptable to the GRT community have all been introduced and recommended by a trusted source, such as a traveller liaison organisation. It is very unlikely that Genomics England will access this community without the support of such organisations**.

Their **fear is that health services are often using healthcare to disguise their real motivation of monitoring the traveller community**, to find evidence that might support judgements to show the community in a bad light, and be used for unfavourable outcomes such as moving them from a site or putting their children into care.

There are several cultural memories on which the GRT's mistrust and fear are based on when it comes to medical research, and add fuel to the fire of mistrust and conspiracy theories. The main one mentioned is the Holocaust, particularly for the Roma community who remember the Holocaust as the Roma Genocide, and they fear this could happen again. There was also a scandal in Sweden of Romani women having enforced sterilisations, often without knowledge or consent. And there is the fear this could happen again. The fear that these types of incidents could happen again is prevalent in the Roma communities.

There is a double barrier to overcome: these communities still face discrimination in healthcare settings, and this hurdle needs to be addressed also to help traveller families trust healthcare professionals and health research.

Belief systems

Traveller communities tend to be very religious, particularly the Irish traveller community. They hold strong Roman Catholic views. The views which particularly influence how they feel about this study are:

- The belief that how we are born, including illnesses and disabilities is "God's will", and that this should not be "tampered with".
- A fear that medical intervention might have a negative impact on a baby's soul
- They can be very wary of any healthcare that tampers with the body, such as needles.
- The Catholic Church has a strong influence over their beliefs, attitudes and behaviours generally. This is also the case for healthcare. For example, in 1976 the Pope's Ethics Committee was concerned about a chicken pox inoculation that was apparently tested on an unborn fetus. And it is only now that the current Pope has said that it is OK to use the vaccine that the community is getting vaccinated again.
- One participant said that a child with a long-term illness is seen as a gift from God, and that the whole family group together to provide care for that child. That said, another community leader working with the Roma community said that disability and long-term illness is a taboo subject, and they fear these children will be taken into care.

Social norms

Research with GRT-supporting organisations highlighted a diverse array of norms which may influence participation in the NGP. These include norms around coming of age, authority and gender roles:

- Young people are considered adults at a younger age than mainstream society, often at age 13.
- Girls and women are rarely in employment. They tend to get married as teenagers and have children when they are aged 18-25.
- Elder women have the most influence within the community. Elders are typically in their 40s. They have the most influence and life experience for the family. They are the ones most

able to persuade other members of the community. However, the men often have the final say.

- Men tend to focus on labour and wages. They are less open to new ideas, or knowledge about the family and wider community views. They can often be more religious, or more likely to veto things on religious grounds.
- Elder women have more knowledge about families, but men are starting to slowly be present at births and to be more involved in childcare. They are “about 40 years behind” on these issues.

Within-group differences

As the findings in the previous section have alluded to, there are significant differences between Gypsy, Roma and Traveller communities, for example in terms of religion and history.

In addition to these broad differences, there is a range of domicile types across each of the traveller types. Some are settled into houses, others are on permanent sites while there are still travellers who live a nomadic lifestyle. Each of these present challenges when trying to engage and communicate:

- Nomadic travellers can be away from services and main healthcare providers for months at a time, and may be difficult to track for longitudinal initiatives
- Those living on permanent sites are more likely to have built up relationships with an organisation that works closely with them and to have consistent access to healthcare, but they will not accept strangers onto their site
- Settled travellers can be harder for services to access, as organisations do not always know where to find them if the travelers do not proactively seek the services out.

4. Responses to the NGP

This chapter provides an overview of the aspects of the NGP that participants said could limit parents' willingness to give consent. In total, **11 aspects of the NGP were identified as potential causes of concern for parents from the five ethnic backgrounds who took part in this research**. These are:

1. The Genomics England / NHS partnership
2. Doubts about the value of genomics research
3. Doubts about the morality of genomics research
4. Concerns about targeting specific ethnic groups
5. Recruitment and onboarding processes
6. Taking samples
7. The database that is used to hold newborns' genomic data
8. How the data will be used, by whom, for what purposes
9. Feedback of findings to parents, and the consequences of a genetic disorder being identified
10. Parents' rights and responsibilities after consent has been given
11. The Baby Ali video

For each of these aspects, this chapter aims to explain why they could present a barrier by drawing on the contextual factors examined in the previous chapter. This chapter indicates the prevalence of concerns on each of the 11 items listed above. These indications are based on the frequency with which codes for each aspect were generated by the analysis. While helpful for getting a sense of how commonly a particular issue was raised during conversation, these indications should not be interpreted as evidence of the likely prevalence or intensity of parental concern about a particular aspect of the NGP.

4.1. The Genomics England / NHS partnership

The role of awareness and perceptions of Genomics England and the NHS in shaping parents' attitudes towards the NGP was discussed by participants in the Black Caribbean, Pakistani and Indian groups.

With regards to Genomics England, concerns focussed on the belief that parents are unlikely to have heard of Genomics England. Its status as an unknown, unfamiliar organisation may lead to feelings of distrust. Moreover, its status as a company may trigger associations with private sector interests, again contributing to distrust.

> *"Genomics England - who owns that company? Is there any private sector ownership of any sheer percentage?"* – Black Caribbean community stakeholder

The lack of awareness of Genomics England stands in stark contrast with public awareness of the NHS, which is much higher. **Some participants thought that parents might trust the NGP**

more if it was purely NHS-owned, and were concerned that the involvement of Genomics England might detract from the halo effect that the NHS brand might otherwise provide. There was also concern about the perception of the NHS brand being used as means of drawing people in.

> *"I think what's quite striking is it's not actually like the NHS. I think people will kind of be a little bit like, oh, hold on a second. I think people have a certain level of trust when it comes to the NHS, and if it's described as not necessarily being the NHS, even though it's like an additional service too, I think that's going to kind of be like: 'hold on a second, who are these people? Are they using the NHS to kind of draw us in?'"* – Black Caribbean community stakeholder

However, the perception of the NHS as trusted was not universal. For example,, one participant in the Pakistani cohort noted that the association with the NHS may act as a barrier to parental consent. This concern was due to members of the Pakistani community believing that they are at risk of being mistreated within the healthcare system because of their ethnicity and religion.

> *"The fact that later on it says that this might become part of the NHS, I think might worry some people…Thinking particularly about the Pakistani community, the distrust that's there is largely because of the treatment that they've had through the NHS…with regards to the way the NHS delivers things like things like treatments or programs, they feel that they're underrepresented."* – Pakistani community stakeholder

4.2. The value of genomics research

The belief that parents might not understand or be motivated by claims about the value of genomics research came up frequently during this research. This belief was expressed by participants from all five cohorts and related closely to participants' views regarding parents' prior awareness, knowledge and understanding of the following areas:

- Genetics and genomics in general
- The role of genes for health, specifically
- The value of medical research

Participants from the Black African and Black Caribbean cohorts additionally highlighted that Black parents may have doubts about the value of genomics research for them and their communities, specifically. These doubts may be related to cultural memories of exploitation of Black communities as part of medical research designed to benefit other ethnicities, most notably white groups.

> *"There's the guinea pig aspect, that you're using me…as an experiment. It's also [the belief that] if it kills me, I'm nothing to anybody, really. So if it happens to me, I'll just be one number, you understand? Who's going to fight my corner? Who's going to use me? And then you just throw me away. I think it still comes from that inequality, that racism issue."* – Black African community stakeholder

4.3. The morality of genomics research

The belief that some parents might have doubts about the morality of genomics research was closely connected with the view that many people within specific ethnic groups are religious. The potential for religious doubts to limit parental consent was noted by participants in all five cohorts.

> *"If you're [a] practising Roman Catholic, which a lot of Pavi or Minko or Irish Traveller people are, then that could be an issue. A mum might be up for it. She might think, yeah, I want the best for baby, I want to try this. But the dad might be very staunch Catholic and insists that it goes against God and therefore that is not something that we should be doing. So unless the Pope decrees it's fine to go ahead and do run some research, people might say: we can't do that. That goes against God."* – Gypsy, Roma or Traveller community stakeholder

While more often considered a potential barrier, **participants from the Indian cohort noted the Hindu and Sikh concept of *sevā*, or selfless service, could help motivate participation in the NGP**. *Sevā* is a central concept in both religions, referring to acts of selfless service that are performed without any expectation of result or award for performing it.

4.4. Concerns about 'targeting' specific ethnic groups

Some participants suggested that parents would be worried that their communities were being actively targeted by the research. This perception was seen as likely to fuel deep distrust in the NGP.

> *"[There may be] mistrust if people think they are being targeted because they're from a specific cultural group or a race group."* – Indian community stakeholder

To counter this perception, **participants felt that it was important to communicate that this study is for all, not just specific ethnicities**. At the same time, however, participants noted the need to balance perceptions of inclusiveness with perceptions of relevance and benefits to specific communities. Striking this balance will be important to demonstrate the study's trustworthiness, but may be complicated by limited knowledge and understanding of research, statistics, and why representation matters.

> *"It's important to say that certain people are underrepresented, but it's quite important not to look as if something's being targeted….I mean, I understand that, but someone might say, well, why are we being targeted? Again, because you're after people from this group and this group and why do you want to know that with us?"* – Gypsy, Roma or Traveller community stakeholder

4.5. Recruitment and onboarding processes

There were two broad concerns about the recruitment and onboarding process.

First, **participants expressed concerns about the impact of talking to parents about genetic conditions during pregnancy**. There was a perceived risk that doing so could add to the stress of a pregnancy. This risk was considered more severe for vulnerable expectant mothers, such as those who have experienced domestic abuse or who have recently migrated to the country and so may be less familiar and/or comfortable engaging with the UK healthcare system.

> *"I think when you're vulnerable already…something like this, depending on when it's pitched to them or they take part in it, it can just be another thing that can be quite worrying and daunting."* – Pakistani community stakeholder

Second, **participants noted that some parents might be reluctant to engage with the NGP if they thought that others within their social network were being recruited too**. This was because of parents being worried that others within their social network would learn about the NGP, which in turn could lead to friends and family members shaming the parents if they provided their consent to participate. This concern was commonly voiced by participants from Pakistani communities, reflecting their views about the centrality of injunctive social and religious norms in regulating the behaviour of people, especially women, in Pakistani communities.

> *"It would also stop them if on that research, there are other people that are also friends and family, they're probably not going to want to do it because the whole 'what comes out' kind of information."* – Pakistani community stakeholder

4.6. Taking samples

References to parents worrying about the invasiveness and potential harms of the procedure for taking DNA samples from a baby were relatively common across all cohorts.

Unsurprisingly, participants said that parents who perceive a potential risk to the health of their baby would be very unlikely to give their consent to the NGP. From discussions with participants, it is also clear that **perceptions of different sampling methods vary**, with some being seen as safer (for example, because they are seen as more routine), and others riskier (for example, because they sound more invasive, or because they are less familiar). It was also clear, as the quote below suggests, that interviewees themselves sometimes misunderstood when samples would be taken – for example, by assuming that blood would be taken from the placenta while the baby was in utero.

> *"When they take any tests from a child, I know the saliva might not be that difficult, but when they take something from a child while he is in mother's womb, would that be not risky?"* – Black African community stakeholder

As well as risk perceptions associated with the method used to gather the sample, participants also flagged that perceptions of 'mistakes' by the NHS may increase some parents' concerns of risks to their baby.

> *"Everybody knows what has happened in the NHS. There's been a lot of mistakes. Some people have lost their baby because of negligence and people don't want to fall into that category."* – Black African community stakeholder

4.7. The database used by the NGP

Participants suggested that parents may be unwilling to participate in the NGP due to concerns about the database[1] that would used to store the data, including:

- The types of data that will be stored on the database
- The security of the database
- The length of time for which data will be stored on the database

Regarding the types of data to be stored, **participants noted (and also sometimes personally expressed) the belief that DNA is a special category of personal data because of its power to identify a person**. There was also evidence of uncertainty about how this special category of data could be used in the future as technologies develop, and the risks these may present to parents and their children.

> *"I think within the Black community is believed that if you drink out of a glass and somebody can take your DNA off it, they'll know absolutely everything about you and your makeup from that."* – Black Caribbean community stakeholder

Participants also highlighted **the potential for parents to be worried about the linking of genomics data to other forms of personal data, such as postcode and medical records**. Such worries were linked, on the one hand, to parents not being sufficiently informed about the need for such data linkages, and, on the other, suspicion that these linkages will be used exploit their children and their communities in some way.

> *"I think the concern there might be that, yes, you may have access to some information related to the genetics, but then you are getting information about everything. So everything is being shared with the research, rather than parents might not see that every thing might be linked to the genetic concern."* – Pakistani community stakeholder

Concerns about the identifying power and potential for abuse of the database were noted as an important driver of worries about data leaks.

> *"Leak of data would probably be the obvious concern…Is it a full DNA sequence that they get? And if that is the case, then what you've been in effect got is you got a fingerprint of a person in a data file and if that gets leaked, somebody else now has that information today. That might not be so much of an issue because, from my understanding, we're very much at an infancy of doing any kind of genetic manipulation, but in the future, that might be a significant thing."* Pakistani community stakeholder

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[1] The National Genomic Research Library (NGRL)

As well as concerns about data storage security, **multiple participants believed that parents would question why the data had to be stored for 16 years**, which was seen as a long period of time. Such questions may arise because of:

- limited understanding of the requirements of the study itself;
- the belief that, the longer the data is stored, the higher the probability that a security breach will occur; and
- the belief that, the longer the data is stored, the longer there is a risk that it will be used in a harmful way.

4.8. How the data will be used, by whom, and for what purposes

Participants across all five cohorts highlighted the potential for parents to be put off by concerns about how the data will be used, by whom, and for what purposes. These concerns were linked with several factors, including:

- beliefs about how genomics data could potentially be used;
- distrust in the motives of specific types of organisation (e.g. pharmaceutical companies, public services); and
- uncertainty about who exactly would have access to the database.

As noted in Section 4.7, participants provided evidence of beliefs in the exceptional identifying power of genomic data. For groups who have experienced persecution at the hands of public authorities, this can contribute to worries that the NGP will be used as a tool for surveillance.

> *"People would definitely worry about confidentiality, how it will be used. All sorts of people will have access to their child's information throughout the day, for 16 years or so. I think that would be something which would be really worrying for a mother. The Roma were experimented on during the Second World War by Nazis, and they were targeted because of their ethnic identity. And although it's been quite a long time ago, people are still worried and still remember."* – Gypsy, Roma or Traveller community stakeholder

Participants also suggested that **people may be unwilling to share genomic data with specific types of organisations, such as pharmaceutical companies, due to concerns about their profiteering, self-interested motives**.

4.9. Feedback of findings to parents, and the consequences of a genetic condition being identified

Participants said that parents would need more information about what happens after consent is given, if they are to feel comfortable giving their consent. In this context, by far **the most dominant concern that participants thought parents would have concerned the return of findings that their child has a genetic condition.**

Participants highlighted that, for some parents, the very prospect of learning their baby has a genetic condition could lead them to decide not to participate in the study. Reasons for this included:

- fear of stigma attached to giving birth to a baby with a genetic condition;
- fear of being faced with a "moral dilemma", in which parents feels like they will need to decide whether to keep their child or not; and
- fear of the knowledge that they (and members of their family) might be carriers of a genetic condition.

> *"[Pakistanis would be unlikely to participate because] the shame it brings upon you if your child is genetically disabled."* – Pakistani community stakeholder
>
> *"I think there's a bit of fear as well. Like a lot of people, they just don't want to know."* – Gypsy, Roma or Traveller community stakeholder
>
> *"They would be fearful that if there is a long term genetic issues that sort of pass down from generation to generation, that they would have to seek help every time the pregnancy takes place."* – Indian community stakeholder

To counter these challenges, **participants spoke strongly about the need to be clear about the levels of support available to parents if their baby is diagnosed with a genetic condition**. This communication would need to overcome the following hurdles:

- perceptions that some ethnic groups are not as much of a priority for healthcare;
- perceptions about the current state and capacity of the NHS to meet demands for additional care; and
- social risks of people other than the parent finding out about a child's condition.

> *"I feel like a lot of people in our community, they kind of feel like they're not prioritised, especially people from kind of low income houses or single parent households. I think that the worry for them is actually, okay, you're going to do this, but then what help is available afterwards? And if it was to affect the child, what would happen after that?"* – Black Caribbean community stakeholder
>
> *"I guess the positives are that something's being done that could help babies at a much faster rate, but that is also dependent on the NHS because we know that currently it's in a shambles, and that the government are not supportive."* – Pakistani community stakeholder
>
> *"[Parents] will want to know who the information will be shared with. Like you said, there's no way of identifying the child. But if we're doing research in the community and there's a set of Asian Pakistani parents, for example, they'll all know. And if someone knows that some are identified as not having a genetic disease and the others are, we'll have a rumour mill."* – Pakistani community stakeholder

4.10. Parents’ rights and responsibilities after giving consent

Several participants reported a lack of clarity regarding how much involvement would be expected from parents in the study, should they give their consent. If parents themselves were to lack clarity on this issue, participants felt that this would be a barrier to them giving their consent. This barrier was linked to three cross-cutting factors, and one additional factor specific to Gypsy, Roma or Traveller communities:

- Parents lead busy lives and have lots of responsibilities, limiting the amount of time and energy available for them to dedicate to participating in research.
- Parents may be concerned about financial costs, for example costs incurred through having to travel to and from hospital
- Being repeatedly engaged as part of the research increases the social risks of family and friends finding out that parents gave their consent to the study, and/or that their child has a genetic condition
- Nomadic Gypsy, Roma or Traveller communities can be away from services and main healthcare providers for months at a time, and may be difficult to track for longitudinal initiatives. GRT communities who are settled on a specific site may still not be reachable via postal methods, because they do not have a registered address

> *“Will they be called upon all the time or will it involve a long term commitment that they're making? That would be one of the concerns that they would have, and also whether it would cost them anything.”* – Indian community stakeholder

> *“The difficulty is continuity of care with people moving about. I'm forever ringing hospitals up, telling them not to change the address that's down for the person, which will be our office care of address. Because they'll go in and say, oh, I'm behind the Midland pub or something like that. And the nurse changes the address that's on the system. The common sense should tell him there isn't going to be a letter that's going to be delivered to behind the Midland pub. But believe you me, we've had that somebody trying to deliver social care products like that, when they're supposed to bring them to the office so that we know that we get them here.”* – Gypsy, Roma or Traveller community stakeholder

Participants also noted a lack of clarity around parents’ rights to withdraw consent after it has been provided. Giving parents the ability to withdraw consent was considered an enabler of participation, as it would provide them with agency and control of their baby’s data. Assuming they had this power, **participants said parents would also need clarity regarding the process for withdrawing consent and the deletion of their baby’s data from the database. They would also need reassurances that requests for data deletion requests would be honoured by other research organisations with access to the data**.

> *“After I ask you to delete my data and you say yes, what power do I have to ask the pharmaceutical company to also delete it? If they do have that power, be*

> *transparent and explain to people in detail, then people will be okay with it." –* Gypsy, Roma or Traveller community stakeholder
>
> *"Can you change [your consent decision] once you've given that information, once you've signed up to say, yes, I'm quite happy for this data to be shared? Because things change. Is that a possibility?"* – Gypsy, Roma or Traveller community stakeholder

4.11. The Baby Ali video

Participants expressed generally positive views about this video, saying that they could understand it and agreed that it engaged with many of the questions that members of their communities would have about the study.

However, while it worked for them personally, **some participants doubted how effective it would be if shown to parents and members of the wider community**. These doubts were expressed most strongly by participants from organisations working with Black African and Gypsy, Roma or Traveller communities. **Even participants who thought that the video was good suggested that it may not be sufficient to shift more entrenched attitudes of distrust**.

Other critiques of the video included:

- that it lacked personalisation to specific groups. Participants provided varied recommendations for how greater personalisation could be achieved, including:
    - by referencing genetic disorders that are common for a particular ethnicity (e.g. sickle cell), and
    - by including more recognisable representations of specific ethnicities (e.g. people in the video wearing traditional Roma outfits).
- that it risked overloading audiences with information, due to the number of questions included. This was an issue for Gypsy, Roma or Traveller participants in particular, who referred to the typically low education levels of members of their communities;
- that it used terms that audiences would find difficult to understand, such as genetic condition, genome sequencing, study pattern, and DNA; and
- that it used metaphors, such as 'guinea pig', that do not always translate well and which may be misunderstood.

5. Attitudes towards the all-in consent offer

5.1. Overview of key findings

This section provides an overview of participants' responses to each component of the NGP's all-in consent offer. These responses suggest that:

- Much of the language used to explain the consent offer to participants during the interviews was too complex and technical[2]. Participants believed that this would cause problems for parents with low **prior knowledge** of genetics, genomics research, and scientific research more generally.
- Certain parts of the consent offer (notably parts 3, 4 and 5 – see below) were widely viewed as poorly defined and open-ended. Participants believed that parents with low **trust in institutions** would be unlikely to provide their consent to these parts of the offer as they currently stand.
- Each component of the model is associated with its own set of questions and concerns that parents may have. While this means each component could act as a barrier, this also presents an opportunity to tailor communication of each component so that it addresses these specific concerns at the outset. The key questions which could be answered when explaining each component of the offer are summarised in Table 2.

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[2] As is noted in the Strengths and Limitations section of this report, the All-in Consent Offer video was developed in a short timeframe and did not benefit from pre-testing with viewers.

Table 2: Key questions associated which consent offer components

Component	Key questions that could be addressed
1. Return of actionable findings	• What support will be available if my baby is diagnosed with a genetic condition? • How will these findings be communicated to me, and how can I be sure that they will kept private from others?
2. Research on newborn screening	• Are there any risks to my baby because of how you will take samples? • How and why will my baby's genomics data be linked with their medical records (or any other personal or sensitive data)? • You're taking the sample to screen my baby now – why do you need to keep that data for 16 years?
3. Research on broader healthcare questions	• How do I know the database is secure? • What types of broader healthcare questions will my baby's data be used to answer? • Why do pharmaceutical companies need to be involved? • Can I withdraw my consent, and if so, how do I know that my withdrawal will be recognised by other organisations with access to the database?
4. Permission to recontact about further research	• How many times will I be contacted? • How can I be sure that communication about further research will be kept private from others? • How much time/energy/money will it cost me to respond to/participate in these follow-up opportunities? • Do I have a right to refuse participation?
5. Use of leftover sample	• Why would there be any leftover sample? • Why is it important to store this leftover sample? • How could this leftover sample be used, by whom, for what purposes?

5.2. Key findings for the five consent components

Part 1: Return of actionable findings

- The actual content of what parents are being asked to consent to was not perceived as a barrier to parental participation
- However, across all groups, participants recommended that the language used to communicate the request be made far more accessible
- In the way in which the part of the model was communicated during the interviews, some participants initially struggled to understand what was being requested
- There were also some specific concerns over what 'actionable findings' mean in practice, as well as calls for more clarification over what support would be offered in the event that those findings including diagnosis of a baby as having a rare genetic condition

Part 2: Research on newborn screening

- This was generally perceived as uncontroversial by most participants, and therefore unlikely to trigger concerns in parents
- However, **the 16-year duration of data storage did cause some participants to recommend more information to clarify why data had to be kept for so long**, and to also ask questions about parents' options for withdrawing consent and being forgotten by the programme
- Some participants also queried how the data from the screening process would be linked with NHS records, as well as the implications of this linkage for their baby's privacy

Part 3: Research on broader healthcare questions

- Prompted strong concerns due to the vagueness of what is meant by broader healthcare questions. Participants expected parents to want more specificity about what kinds of questions would be investigated using their baby's data
- Also prompted strong concerns due to the ability of private pharmaceutical organisations to access the database

Part 4: Recontact for follow-up data requests and notifications about future opportunities

- Like Part 1 of the consent offer, multiple participants found the language used to communicate this model difficult to understand
- Several participants suggested that parents would find the information that they can refuse consent to future research reassuring
- One participant also recommended this aspect of the process be expanded upon, as a regular feedback mechanism for parents to stay in the loop about what is happening in the programme

Part 5: Use of leftover samples

- **This was by far the most concerning aspect of the consent offer**, and the one that most participants felt would lead to parents refusing to give consent
- Participants thought that the purposes to which this leftover sample could be put are too vaguely defined, particularly given the fact that the data is being stored for 16 years
- **Some participants could not understand why there might be leftover samples**, or why they need to be stored in the first place. These uncertainties may contribute to suspicion and distrust
- In relation to further research, this part of consent model prompted some participants to ask whether parents would be recontacted for consent to new research involving their baby's sample

6. Implications for Genomics England

6.1. Approaches to enabling expectant parents to participate in the study, should they wish to

Through this research with community stakeholders it was apparent that there will be a variety of issues for the NGP to overcome to enable expectant parents to participate in the programme. These are covered in detail in the preceding sections of this report and relate predominantly to **interlinked issues of trust and understanding**. Health research is an emotive and sensitive topic and one for which there are many misconceptions and negative historical associations for members of some ethnic minority communities. It will be important to address these issues to ensure that parents from these communities have the opportunity to participate in the NGP should they want to.

> *"The narrative shouldn't be how to convince people but how to* educate *them so that they can make informed decisions."* – Black African community stakeholder

Awareness raising activity

A lack of awareness and understanding of health research will hamper community engagement, particularly where terms like 'health research', 'DNA' and 'genetics' either:

- carry with them negative associations for particular communities (such as Black Caribbean and Gypsy, Roma and Traveller communities), or
- create a barrier for engagement due to their medicalised terminology.

To enable people to meaningfully engage with the NGP, including parents consenting to participate, there is a need to raise awareness of the NGP as a means of benefiting the health of the population inclusive of the variety of ethnic communities involved in this research.

At an overarching level, **there is a need to raise awareness of the NGP amongst the broader population to help normalise this form of health research and to ensure that the NGP is seen as something that is involving all groups within society, and not just specific ethnic minorities**. This is likely best achieved through mainstream media and social media campaigns that introduces Genomics England and the NGP. This will need to "go back to basics" on health research, genes and DNA, inherited conditions and the rationale for the NGP. **Stakeholders recalled campaigns on organ donation, health screening and diabetes which were felt to offer good examples of ways to raise awareness of health-related issues**.

> *"Look at the blood banks and the messaging around that: donating', 'saving lives', - this is making it easier for people to get involved and is saying that 'if we don't do this, x will happen'. This has been communicated over time via leaflets, clinics etc and is making an impact on people's willingness to donate."* - Black African community stakeholder

There was recognition and understanding that more tailored engagement would be required with specific communities given different sociocultural norms, associations with health services and health research, and language and literacy needs. This more tailored engagement would need to address more specifically:

- what is health research?
- what is Genomics England and what is the NGP?
- what is the relationship between Genomics England, the NHS and other researchers?
- what is Genomics England aiming to achieve through the NGP (i.e. the benefits)? and
- what are the risks involved in participating in the NGP, and what reassurances are offered around safety from physical harm, data security and any of the community-specific barriers already identified in this report?

> "Give a vision of the journey: what's at the start, what's involved, what gets kept, what access rights people have with their data, being clear about withdrawal - how it works and how long it takes." – Black African community stakeholder

> *"What does support look like, based on where people live? Will people be profiting disproportionately?...If something is found and it's curable, what are you going to do about it, and if not what other types of support are available?"* – Black Caribbean community stakeholder

In engaging with individual communities (which may be geographically localised communities and/or ethnic-minority communities specifically), **it will be important for Genomics England to be clear on the purposes of their engaging these communities. There will be a fear of being targeted because of their ethnicity, and this needs to be allayed through being transparent about the aim of being inclusive and recognising that different communities have different understanding of and associations with health research**. Recognising the validity of these concerns will be an important part of building a trusting relationship.

> *"Reparations is important, reflecting on the damage and the repair, not the trust that needs to happen. Think about how to centre this in the work."* – Black African community stakeholder

> *"I think one of the most important things is to make sure that people don't feel that they're being targeted because of their ethnicity, because that's where the risk will come in. Because of the databases, you know, getting information about ethnic, ethnic communities, that could be a risk."* – Gypsy, Roma or Traveller community stakeholder

More tailored community-specific engagement was seen as best achieved by working through trusted intermediaries. These could include VCSOs such as those engaged in this research, or health practitioners such as GPs, pharmacists or nurses from within the communities. **Working with and through trusted health practitioners that work within and are 'from' the communities to be engaged will help confer trust in the study**.

Different approaches to engagement were felt to work with different ethnic groups. This suggests that **bespoke engagement approaches may needed for different ethnic groups**. For example, within Gypsy, Roma and Traveller communities more of a face-to-face in-person approach was seen to be important in facilitating trust. Within Indian communities this could be more one-to-many via outreach events at religious festivals given increased health literacy and associations between the NGP and doing a 'social good'. Amongst the Pakistani, Indian, and Gypsy, Roma or Traveller community **it was felt to be important to get (Islamic, Hindu and Roman Catholic) faith leaders on board in raising awareness and sanctioning participation in the NGP**.

> *"In the past, for the vaccination, for example, we were asked by NHS England do awareness raising within the Indian community. So, with the Hindu community, we've got a religious scholar who is well recognised, well renowned. And we got him to record a message about the vaccination. And he also said, 'I've taken the vaccination. Soon as we got that recorded and sent that via the various groups, people started to come forward."* – Indian community stakeholder

> *"It's very important to use homegrown Imams and not imported Imams, because the younger Imams have an understanding of the dynamics within the community, they speak the language that young people speak. The other thing, if we're talking about men educating or being involved in this campaign, I think really role models, people like Aamir Khan, so you've got the eyes and ears of younger people, and you've got the eyes and ears of the men in the community."* – Pakistani community stakeholder

Finally, **there will be a need to communicate directly with expectant parents**. This communication would be expected to come through conversations with health practitioners involved in their care during the pregnancy. The information would build on that detailed above, focusing on:

- how the process would work in practice (both in collecting the sample and longer-term engagement);
- the personal benefits of participating and any associated risks; and
- what form of support would be provided should a genetic condition be identified.

> *"People are looking at the here and now, so any benefits that address the long run just aren't going to land significantly, especially if they are in 'tunnel vision' mode. How is this going to help them now?"* – Black African community stakeholder

Early engagement with parents was seen to be important to raise awareness and familiarity with the NGP and the process of participating, though more detailed information should only be introduced during the second trimester where there is lower risk of a miscarriage.

> *"It should be on the radar as early as possible/before pregnancy but more in-depth halfway during the pregnancy so as not to add to the stress of having a baby."* – Black Caribbean community stakeholder

The importance of transparency on risk and reward

There was felt to be significant mistrust of health research amongst many of the communities involved in this research, often because of negative past experiences within the communities themselves. These were typically where the purposes for collecting data (or the subsequent use of that data) was not what people had knowingly consented to. In many cases, the data (or process of collecting the data) was harmful to the individual providing the data. As such, **there was concern around the level of risk that individuals were exposing themselves to in participating in the NGP, in particular where their data may be used in the future for as yet undefined purposes by undefined organisations**.

In demonstrating the trustworthiness of the study to individuals and communities, stakeholders were clear that it was **fundamentally important that communications were fully transparent and honest** around:

- who will have access to their data and how data may be used in future, including who will stand to benefit from this, and
- what the relative risks are for individuals participating in the NGP, and what the associated benefits are.

When communicating benefits it was felt to be necessary to be clear on what can or cannot be promised to participating parents around the type of diagnoses that can be made, their accuracy and what can be done in response to any conditions that are identified. Being transparent about these issues was felt to be necessary to both address concerns that individual parents might have, but also as a prerequisite for engaging the support of stakeholders.

> *"Communicate the goal - we might not get it 100% right the first time but that's why we need to* have a sample" – Black African community stakeholder

> *"Trustworthiness is being able to address and clearly answer questions like 'Who owns the data/the organisation? How do they decide who to share the data with?"* – Black Caribbean community stakeholder

> *"The way it's been approached with me, it's complicated, something that could be so made so much more simple. And the word risks. I've not heard what the risks are yet, but I've keep seeing the word risks. And that makes bells ring for everybody, I think. I mean, what are the risks? And you know, unless we're going down the line of, sort of Big Brother and everybody being in some massive database and all of that."* –Gypsy, Roma or Traveller community stakeholder

Developing appropriate engagement materials

Common feedback from participants in this research was that the **terminology used in introducing the NGP programme will be instrumental in how people respond**. Terms like 'genome' and 'DNA' are not well understood, sound highly medicalised, scientific and form barriers to people engaging further. They also carry with them associations with negative historical and sociocultural events (e.g. the Alder Hey organs scandal, the Tuskegee syphilis study) which can form strong barriers to further engagement amongst certain communities depending on how resonant these associations are.

Given identified issues with the terminology and with language and literacy, stakeholders highlighted the importance of using plain English, and where possible making any engagement material highly visual (i.e. using pictures and videos to explain concepts or processes). This was also felt to help with engaging individuals where there were language and literacy issues - where leaflets would not work effectively - though material in languages other than English was felt to be important for certain groups (notably the Pakistani community).

> *"Certainly not written materials, even the so called easy read written materials. Don't go anywhere, perhaps other than in the bin in reality. In the main, it's got to be face to face and probably through a trusted intermediary, either someone who knows the community very well works with them very well, or a nurse. We've got nurses going on several sites now. We would go through our nurses."* – Gypsy, Roma or Traveller community stakeholder

> *"There is a stigma attached to having a child that has an abnormality or something. So, removing that stigma by leaders or known people the community looks up to. YouTube food channels or something, the whole family that you connect with, when they talk about the stigma that, you know, having a child with a birth defect or something is not actually something to be ashamed of, you know, we can actually help each other by understanding how to deal with someone who's got some kind of defect."* – Pakistani community stakeholder

Thinking more broadly about community-level engagement, stakeholders highlighted how many ethnic minority communities have strong oral histories and traditions. **Given that some communities (e.g. Black Caribbean, Pakistani and Roma) are less likely to openly discuss health, one way in which to start conversations within the community could be a theatre play, TV drama or documentary)**. These were seen as effective ways of reaching communities and increasing understanding of the NGP.

> *"Among the older generation, there's a refusal to discuss certain things, especially from a Jamaican background, so be innovative: dramas, plays [to get people talking] rather than just speech or a leaflet."* – Black Caribbean community stakeholder

One way of demonstrating the trustworthiness of the study is for engagement materials to include people from the communities to be engaged (both in terms of their locality and ethnicity). **Communities were seen to respond well to seeing and hearing from other people, like them, that had agreed to participate in the process, including their experiences. Storytelling is a powerful tool, particularly within ethnic minority communities** and these examples (including testimonials) were felt to be important in allaying fears and normalising participation.

> *"It's not just about 'looking like me' but 'being like me'."* –Black Caribbean community stakeholder

> *"That would be very much the same for the Roma. You know, if you have people who decided to take part and then kind of were advocating for it, or like kind of explaining, and, you know, that would really make a huge difference."* – Gypsy, Roma or Traveller community stakeholder

> *"Maybe somebody who already, you know, took part in the research and explaining how it was for them and what it meant and you know, how the familiar children and community can benefit from that and so on would be much more effective with using more visuals and, you know, ordinary sort of language rather than very academic language or, or kind of medical language, which was used in those promotional sort of films."* – Gypsy, Roma or Traveller community stakeholder

Stakeholders flagged that any materials need to strike the right balance between inclusive of a given ethnic community and not feeling targeted at them. In some workshops, examples were given of more and less successful campaigns that were seen to be attempting to engage their ethnic group. Those that were more successful felt more authentic.

As an example, Google Pixel's recent advert featuring AJ Odudu was felt to be slightly disingenuous, despite AJ's humour and likeability. Stakeholders from the Black Caribbean community (particularly the younger ones) felt that it seemed forced and 'too targeted', which jarred.

> *"It's obvious that [Google] are using someone from our community to sell us some*thing." – Black Caribbean community stakeholder

In contrast, We Buy Any Car's recent campaign was seen as a good example of 'zooming out' to portray multiple communities benefiting from a service, communicating an inclusive approach to engagement.

> *"I prefer that advert. I saw people who looked like me and others who didn't.*" – Black Caribbean community stakeholder

> *"Being able to see how other people are getting on would be good. Not just Black people but everyone's experiences…Like when you buy a product, you should be able to see this info on a website, or even FAQs."* – Black Caribbean community stakeholder

Within the Gypsy, Roma and Traveller communities, organisations had had some successes in creating video content from within the community to help raise awareness of different issues. Here it was felt to be important to find people from within the community who have had a positive experience of the NGP to communicate the reasons why they have found it beneficial. In the past, they have created YouTube videos which can be shared on closed group pages (e.g. on Facebook, Instagram, WhatsApp and YouTube) and potentially through TikTok or Twitter for wider dissemination. The community will then cascade.

> *"There's quite a lot of people do use social media. And it is quite popular. We've just done one, locally around the NHS app where community member was talking about how she's first time she'd used etc, etc. And within one day, it had like 450 hits on it. So it's quite, quite popular. If it's authentic, if people from the community are making the video and also clicked in the information that people want to know about something, and then I've asked you the question or explaining how they're doing, it has a lot more resonance with the community."* – Gypsy, Roma or Traveller community stakeholder

6.2. Learnings for how to work with voluntary sector organisations to engage communities

As described in Section 8.1. **there is a role for VCSOs in helping Genomics England to engage with different communities, both at a local (geographical) level and in reaching out to specific ethnic minority communities (including communities not covered by this research)**. These organisations have typically built relationships with their community through many years of close support across a wide variety of issues, and this relationship is one that has resulted in a degree of trust towards those practitioners working on behalf of these organisations.

In engaging with stakeholder representatives of VCSOs working with the different ethnic minority communities of relevance in this research, **it was evident that they would be open to helping Genomics England in engaging with the communities which they supported should it be clear that this was beneficial for these communities**. This might take different forms, but importantly it needed to be based on an **equal and open partnership**.

Some participants were clear that **there should be no excuses for not engaging with ethnic minority communities around health research**. **While these communities may be currently underrepresented, they can be engaged through working through the appropriate channels, notably via VCSOs**.

> *"Current excuses that they can't find enough Black participants, when we have a network of 1000s who are willing to come forward."* – Black Caribbean community stakeholder

Stakeholders highlighted how voluntary organisations will know their localities and communities best, therefore **it will be important for Genomics England to develop working relationships with these organisations at an early stage of the NGP roll-out, to listen and then co-create engagement approaches at more of a localised leve**l. This initial research has started this process already, and provides evidence of where the challenges and opportunities exist with reaching out to members of different ethnic communities. There is an opportunity to play this back and work with these community organisations within the NGP study sites to refine messaging and engagement approaches, tailoring this based on their feedback rather than coming with a set strategy and finalised materials.

Voluntary organisations as 'engagement partners'

VCSOs were seen to offer Genomics England an important 'route in' to different ethnic minority communities. Stakeholders saw the voluntary sector as having a key role to play in co-facilitating engagement within their communities. **They were clear that their role would not be to deliver communications on behalf of Genomics England, but to help provide a platform and be present at points where Genomics England (or local healthcare practitioners) are engaging with a given community** to help ensure a dialogue and address points that may get 'lost in translation'.

> *"it is important to say this is what Genomics England is trying to do. It's about open, transparent communication, you know, where we are, at this point, what the timeline and how everything is progressing. You know, the more information the organisation gets, they can actually benefit it getting it down to their service*

> *users. And I wouldn't say it's an easy task you guys got, it will be a mammoth task, but it can be achieved. But you know, you've got to constantly keep on engaging with the community."* – Indian community stakeholder

There was acknowledgement that there are many different organisations working with communities, therefore **Genomics England needs to take care not to tie themselves to particular organisations at the expense of wider engagement given the potential for excluding different sections of a community** (e.g. working within different locations or with different nationalities, genders, religious subgroups).

Another consideration is **avoid focusing solely on organisations tied explicitly to an ethnic minority community (or nationality), even when seeking to engage that community**. There are many organisations that play a more cross-cutting role within a community that may be well placed to support Genomics England. **While it makes sense to focus on those organisations that are providing health-specific or more generic support to the community at a relatively broad level (i.e. not focusing on the most disadvantaged sections of a community), these may not be ethnicity specific**. For example a Christian church or foodbank may work with people from an array of different ethnic groups.

> *"[While we've highlighted the Nigerian, Somali and Eritrean communities], we don't have to get every single community - it's important to think of the meeting points. A physical eg: People might meet at church, but everyone has another community… Personally, I'm connected to 34 other organisations of all different backgrounds via Leeds City Council though my organisations food bank. Leeds City Council shares the information from organisations on a shared platform and the community liaisons can then pass the information onto their communities."* – Black African community stakeholder

Similarly, **stakeholders cautioned against engaging community 'leaders' who are positioned as 'representing' a given community. Instead they should look to engage widely and to work with practitioners who have a more grassroots role**.

> *"They need to start by changing that word from 'community leaders' to 'community workers' 'cause straight away that's going to have alarm bells ringing like 'hold on, who says you're the community leader"? Community workers and community leaders are quite different. So you might do a lot of work in the community, but are you a leader in that sense, because it has a lot of connotations that word, leader. I think they need to take that out of the vocabulary straightaway… in my community, people are referred to in the press as 'community leaders and that can cause uproar - just because you're speaking out, that doesn't mean you're the leader."* – Black Caribbean community stakeholder

Voluntary organisations as 'recruitment' partners

We have already highlighted how important stakeholders felt it was for members of their communities to be able to hear about the NGP from people that 'looked like them' in terms of having some shared characteristics. **One way in which VCSOs might be able to support Genomics England was through providing them with access to volunteers – members of their local and/or ethnic community – who could help provide outreach support**.

These volunteer ‘champions’ were seen as helping to raise awareness through sharing information about the NGP within their community through leaflets, flyers and social media, and most importantly through holding conversations with people. Despite some of the language used by stakeholders in the workshops, there was agreement that the focus of these conversations should be on helping educate prospective parents to enable them to make an informed decision when asked if they would like to participate in the NGP, rather than to convince parents to participate.

> *“I'm a fan of champions or ambassadors created from those communities. So if we train them up, educate them, and then give them some incentives to go and do this, they feel empowered to do it.”* – Indian community stakeholder

> *“Creating community champions, training and building capacity so that the work [at a community level] is led for and by. They can learn, understand and ‘sell’ it to their families and communities.”* – Black African community stakeholder

A role for a community ‘champion’ was felt to be particularly important in reaching those individuals who are less engaged with voluntary organisations and/or more sceptical of public health services, and who may therefore not receive information about the NGP from other sources. The other benefit of this is that conversations can be undertaken in languages other than English, helping to address barriers that may impact older generations or those who are more recent migrants to UK.

Addressing key barriers and facilitators for engaging the voluntary sector

There is much good will within the voluntary sector for supporting initiatives like the NGP, which has the potential to benefit the health of the communities which they support. However, stakeholders highlighted **that the capacity of VCSOs is stretched thinly and that, despite support for the aims of the NGP, many organisations will be unable to support Genomics England without additional funding to cover any resource put towards community engagement activities**.

> *“I’d like to know what the time and budget needed for my involvement…There’s a lot of work to be done, and it can’t be done successfully without us.”* - Black African community stakeholder

As well as considering resource implications, there remained a range of unanswered questions relating primarily to how data captured as part of the NGP will be used and safeguarded, which will need to be addressed for stakeholder representatives to be comfortable in helping Genomics England take the next steps in engaging with their communities. **There is a reputational risk involved for organisations in aligning with or aiding Genomics England, and the first step in mitigating this is to work with these organisations to more clearly communicate the NGP**.

> *“I think my advice to Genomics England would be all around clarity, information. And answering the questions that have already been raised, I think they need to do a lot of thinking, if they're serious about carrying this forward, they're really going to have to market it around the benefits the safety. And as I say, at the same time, answer some of the questions that have been raised. It's*

> *not an immediate quick sell."* – Gypsy, Roma or Traveller community stakeholder

> *"We need to be able to deliver this to our communities with complete confidence, we need to be convinced that this is a good thing for our community. And we should be prepared to answer almost any questions. Because what we don't want to be seen by our communities is that we're like a puppet."* – Pakistani community stakeholder

One barrier or challenge that Genomics England needs to account for is the length of time that might be required to introduce the programme effectively at a local level. Given the amount of time between this research and start of the NGP pilot programme, there was a question as to whether there was enough time for Genomics England to identify community partners, engage them to help co-create materials and engagement approaches, and to work through them to reach parents who might participate. There was also consensus that, for this time to be sufficient, **8**.

Getting healthcare practitioners on board from different local ethnic communities was seen to provide a stepping stone to building engagement at a local level more quickly than might be the case otherwise. Healthcare practitioners, like GPs, were seen to be trusted local intermediaries who had the credibility in the field of health to discuss the NGP directly with communities, without this needing to come from Genomics England. The benefit of this is that it felt **less like a national organisation 'parachuting in' and more of a ground-up approach to engagement**.

> *"You can't parachute into the area, you if you've identified your insights, then you start codesigning, coproducing messages, those posters, until you've got the ownership and the buy in from those communities that you're trying to target. And again, that can be done through different ways. It's good to bring on some of the younger generations of young mothers. Also, in terms of GP practices and the primary care networks."* – Indian community stakeholder

7. Final Considerations

Genomics England commissioned this research to better understand how to design and communicate the NGP in a way that is fair and inclusive, removing barriers to participation for expectant parents from five ethnic minority communities.

Through engaging with representatives of 25 organisations, each of whom work directly with ethnic minority communities, this research was able to provide a clear sense of the challenges and opportunities for Genomics England, with implications for communications and engagement approaches both in the pilot programme and any future roll-out of the NGP.

To conclude this report, this section summarises key considerations for Genomics England as it thinks about how to enable parents from ethnic minority backgrounds to participate in the NGP.

Communications

- To enable people to meaningfully engage with the NGP, including parents consenting to participate, there is a need to raise awareness of the NGP as a means of benefiting the health of the population inclusive of the variety of ethnic communities involved in this research.
- There is also a need to raise awareness of the NGP amongst the broader population to help normalise this form of health research and to ensure that the NGP is seen as something that is involving all groups within society, and not just specific ethnic minorities.
- It will be important for Genomics England to be clear on the purposes of engaging ethnic minority communities. There will be a fear of being targeted because of their ethnicity, and this needs to be allayed through being transparent about the aim of being inclusive and recognising that different communities have different understanding of and associations with health research.
- There was felt to be significant mistrust of health research amongst many of the communities involved in this research, often because of negative past experiences within the communities themselves.
- There was concern around the level of risk that individuals were exposing themselves to in participating in the NGP, in particular where their data may be used in the future for as yet undefined purposes by undefined organisations.
- When communicating benefits it was felt to be necessary to be clear on what can or cannot be promised to participating parents around the type of diagnoses that can be made, their accuracy and what can be done in response to any conditions that are identified.

Partnerships – VCSOs

- There is a role for VCSOs in helping Genomics England to engage with different communities, both at a local (geographical) level and in reaching out to specific ethnic minority communities (including communities not covered by this research).

- There should be no excuses for not engaging with ethnic minority communities around health research. While these communities may be currently underrepresented, they can be engaged through working through the appropriate channels, notably via VCSOs.
- To achieve its objectives, it will be important for Genomics England to develop working relationships with local VCSOs at an early stage of the NGP roll-out, to listen and then co-create engagement approaches at more of a localised level.
- The role of VCSOs in community engagement should not be to deliver communications on behalf of Genomics England, but to help provide a platform and be present at points where Genomics England (or local healthcare practitioners) are engaging with a given community.
- Take care not to tie Genomics England or the NGP to particular organisations at the expense of wider engagement given the potential for excluding different sections of a community.
- Avoid focusing solely on organisations tied explicitly to an ethnic minority community (or nationality), even when seeking to engage that community. Organisations that are providing health-specific or more generic support to the community at a relatively broad level (i.e. not focusing on the most disadvantaged sections of a community) may also be valuable partners, even if they are not ethnicity specific.
- The capacity of VCSOs is stretched thinly and that, despite support for the aims of the NGP, many organisations will be unable to support Genomics England without additional funding to cover any resource put towards community engagement activities.
- There is a reputational risk involved for organisations in aligning with or aiding Genomics England. The first step in mitigating this is to work with these organisations to more clearly communicate the NGP.

Partnerships – Other stakeholders

- Participants cautioned against engaging community 'leaders' who are positioned as 'representing' a given community. Instead they should look to engage widely and to work with practitioners who have a more grassroots role.
- One way in which VCSOs might be able to support Genomics England was through providing them with access to volunteers – members of their local and/or ethnic community – who could help provide outreach support.
- A role for a community 'champion' was felt to be particularly important in reaching those individuals who are less engaged with voluntary organisations and/or more sceptical of public health services, and who may therefore not receive information about the NGP from other sources.
- Working with and through trusted health practitioners that work within and are 'from' the communities to be engaged will help confer trust in the study.
- It was felt to be important to get (Islamic, Hindu and Roman Catholic) faith leaders on board in raising awareness and sanctioning participation in the NGP.

Communication materials

- Given identified issues with the terminology and with language and literacy, stakeholders highlighted the importance of using plain English, and where possible making any engagement material highly visual.
- Given that some communities (e.g. Black Caribbean, Pakistani and Roma) are less likely to openly discuss health, one way in which to start conversations within the community could be a theatre play, TV drama or documentary).
- Communities were seen to respond well to seeing and hearing from other people, like them, that had agreed to participate in the process, including their experiences. Storytelling is a powerful tool, particularly within ethnic minority communities.
- Stakeholders flagged that any materials need to strike the right balance between inclusive of a given ethnic community and not feeling targeted at them.

8. Appendices

8.1. Appendix 1: Online survey script

1. What type of services do you provide? Support with:
    a. Education and employment
    b. Benefits and housing
    c. Childcare and parenting
    d. Health and wellbeing
    e. Leisure and sport
    f. Other (please specify)

2. Which local authority (or local authorities) do you work in?

    Open

3. Which of the following ethnic minority communities do you work with?
    a. Asian or Asian British: Indian
    b. Asian or Asian British: Pakistani
    c. Asian or Asian British: Any other
    d. Black or Black British: Black African
    e. Black or Black British: Black Caribbean
    f. Black or Black British: Any other
    g. White or White Other: Gypsy, Roma or Irish Traveller
    h. White or White Other: Any other

[IF respondent selects more than one response, THEN ask Q4. IF respondent selects only one response, THEN skip to Q.5].

4. Which of the of the following ethnic minority communities do you work with the most?

    [Show responses from Q3]

The following questions are about people's awareness and levels of concern about genetic conditions. A genetic condition can be caused in whole or in part by a variation in a person's DNA sequence.

5. On a scale of 1 to 5, how aware do you think members of your local [NAMED COMMUNITY] are about genetic conditions?

6. On a scale of 1 to 5, how aware do you think that members of your local [NAMED COMMUNITY] are about genetic conditions that specifically affect people from their ethnic background?

7. On a scale of 1 to 5, how concerned do you think members of your local [NAMED COMMUNITY] are about genetic conditions?

Each year thousands of babies are born with rare genetic conditions.

These conditions can be devastating – one-third of children with a rare disease will die before their fifth birthday.

The UK Government announced the launch of the Newborn Genomes Programme last year. The programme will be run by Genomics England, a company owned by the Department of Health and Social Care, in partnership with the NHS.

The Programme will explore the effectiveness of studying the DNA of newborn babies to detect whether they are at risk of rare genetic conditions.

There are three potential benefits to this study:

- Where babies are identified as having a rare genetic condition that can be treated in childhood, parents will be notified and will be referred to the NHS for so that they can access treatment and support.
- Digital files of the DNA from up to 100,000 newborns will have identifying information removed. They will then be stored in a secure database. Academic, clinical, and commercial healthcare researchers can apply to access babies' genomes for research purposes. Their research would focus on improving understanding of health and disease, advancing current therapies, or developing new diagnostics and treatments.
- Exploring if storing babies' genomes from birth could lead to new discoveries in genomic medicine through a person's lifetime. For example, clinicians might need to re-analyse babies' genomes later in life if they think that doing so would improve their clinical care / treatment.

In practice, to participate in the study, new parents will be asked to give their consent for midwives to collect a small sample of DNA (often via a blood sample) from their baby immediately following birth. This is similar to the current newborn blood spot test.

8. How do you think parents from your local [NAMED COMMUNITY] would feel about being asked to give their consent for midwives to collect a small sample of DNA from their baby immediately following birth? Are there any key concerns that might be particular to people from their ethnic background?

9. How do you think these concerns could best be overcome to encourage parents from your local [NAMED COMMUNITY] to consider participating?

[IF RESPONDENT SELECTED MULTIPLE RESPONES TO Q3, CONTINUE TO BELOW. IF NOT, CLOSE SURVEY]

At the beginning of the survey, you said you also worked with other ethnic minority communities.

10. How do you think parents from these communities would feel about being asked to give their consent for midwives to collect a small sample of DNA from their baby immediately following birth? Are there any key concerns that might be particular to those communities?

    When writing your response, please specify which ethnic minority community you are talking about.

11. How do you think their concerns could best be overcome to encourage parents from these ethnic minority communities to consider participating?

    When writing your response, please specify which ethnic minority community you are talking about.

8.2. Appendix 2: Interview topic guide

Introduction (5 mins)

My name is [XXX]. I work on behalf of Basis Social. We are an independent research agency who have been asked to carry out this research with you on behalf of Genomics England.

Genomics England is the organisation in charge of the Newborn Genomes Programme. They're going to be running a research study in partnership with the NHS. This research study will explore how, and whether, to offer whole genome sequencing to all newborns. If effective, whole genome sequencing may help with diagnosis and faster referrals to treatments for rare genetic conditions.

Genomics England is interested in understanding the perspectives of community leaders working with people from different ethnic minority backgrounds towards the research study. Specifically, I want to talk to you today about parents from [ETHNIC MINORITY] background.

Parents are important for the research study because they will be asked to give their consent for their newborns to be included in the research study.

Parents from ethnic minority backgrounds are important because, historically speaking, genomic research has mostly involved people of European background.

To counteract this bias, this research study aims to be as inclusive and equitable as possible to people of all ethnic backgrounds.

The goal in speaking to people like yourself, who work directly with members of the community, is to get your views on how to do this well.

The interview will last for one hour. We have a lot to get through so please excuse me if I move the conversation on at times.

We would like to record this discussion but only if you are happy with this. The recording is used to ensure we have an accurate record of the discussion for analytical purposes. With your consent we would also like to share this with Genomics England as they are keen to hear what you have to say directly. Do you have any concerns or worries about this? If you are happy, I'll start recording the session now.

[Gain verbal consent].

This interview is confidential and will be anonymised for the purposes of our analysis. We may wish to use quotes in our report to help illustrate findings. Any quote would be anonymised – i.e., we won't attach your name to anything we quote. Are you happy with this?

[Gain verbal consent]

Basis are a company partner of a body called the Market Research Society and abide by their code of conduct. This means:

- Participation in this discussion is completely voluntary
- You don't have to answer any question if you don't want to, you can just ask us to move on.
- You can withdraw your consent to participate at any point in the process. This includes during this discussion, or up until the report is published at the end of March 2023.

Finally, as part of this interview, we will be sharing some prototypes and ideas for how Genomics England might communicate the NGP research study to members of the public. These may evolve depending on the findings of our conversations in this interview and the later workshops. As such, we request that you treat the material we share with you today with sensitivity and discretion, as it is not yet meant for sharing in the public domain.

Any questions before we start?

NOTE TO MODERATOR: before beginning, acknowledge upfront that we recognise there is going to be a wide variety of views from within each community (ie. There is no one 'black caribbean' view about genomics or research) and encourage the interviewee to note some of these differences wherever possible (e.g. - where they feel people might have a particular perspective when they don't speak English as their first language vs they do, or where they come from a more affluent background vs lower SES).

Module 1: Warm-up - Ethnic minority community attitudes towards participation in health research (5 mins)

1. Please could you introduce yourself and your organisation, and say a little bit about the work you do with members of the [ETHNIC MINORITY] community in your local area.

2. What things might people from your local [ETHNIC MINORITY] think when they hear the phrase ‘health research’?

Module 2: Introducing and gathering feedback on the NGP offer (20 mins)

We'll move on now to introducing you to the Newborns Genome Programme's Research Study in a bit more detail. I'm going to play a short video which is being developed by Genomics England, to explain to parents what the research study is about and what's required from them. It might be helpful for you to take down some notes about what you are hearing. I'll then ask you about your initial thoughts and feedback.

Interviewer plays 'Baby Ali' video (approx. 5 mins).

3. What are your thoughts and feelings having watched the video? Was there anything which stood out? Or anything that you didn't feel was communicated very clearly?

4. Can you explain to me what you think the Newborns Genome Programme's research study is about? I.e. what is the purpose and what does it involve? If not covered, specifically probe on:

   a. the fact that it is a research study
   b. likely benefits (for parents and for wider society)
   c. possible risks of the research study

5. How do you think this study might be received by parents from your local [NAME ETHNIC MINORITY] community?

   Probe for:

   a. What questions might they have?
   b. Where would they look for answers to those questions?

6. How likely do you think new parents from your local [NAME ETHNIC MINORITY] community would be to participate in the study? Why?

   Probe for:

   a. Drivers to participation?
   b. Barriers that might prevent them from participating?
   c. What if anything do you think might help alleviate these fears?

7. [SKIP IF ALREADY ADDRESSED IN Q.6] How aware are people from [ETHNIC MINORITY] backgrounds of genetic health conditions?

   a. What role does awareness play in encouraging people from [ETHNIC MINORITY] to participate in a study like this? Why? Can you give me some examples?

Module 3: Introducing and gathering feedback on the NGP consent model (30 mins)

We'll move on now to introducing you to the Newborns Genome Programme's research study in a bit more detail.

I'm going to play another video which explains how Genomics England plan to ask for consent from parents. If parents give their consent, their baby will become a participant in the study.

This video is a bit longer – nearly 10 minutes. Rather than watch it all in one go, I want you to raise your hand every time the video mentions something that:

- You personally have a question or doubts about
- Gives you any cause for concern / worry
- You think could cause questions / concerns in the minds of a member of the [ETHNIC MINORITY] community

As soon as you raise your hand, I'll pause the video and listen to your questions / concerns. You can raise your hand as many times as you want, at any point during the video.

All clear?

Interviewer plays 'All-in Consent' video (approx. 10 mins)

NOTE TO MODERATOR: the five parts of the consent model are below.

a. Consent to the **return of actionable findings** to newborns' families
b. Consent to **research on newborn screening**
c. Consent to **research on broader healthcare questions**
d. Consent to be **recontacted to request follow up data** related to newborn screening research **or to offer opportunities to participate in other studies**
e. Consent to **use of any of the baby's leftover sample** for further research

When listening to questions / concerns, remind participants that while you may not have the answers yourself, these will be fed back to Genomics England and addressed in the subsequent workshop.

Where appropriate, check to see if information provided by voiceover for each part of the consent model answers questions or concerns, and to what extent.

8. Now that you've watched the entire video, what are your thoughts and feelings about the consent model? Was there anything which stood out?

    a. Probe for more positive / negative parts of the model

9. Given everything you've just heard about the consent model, how likely do you think new parents from your local [NAME ETHNIC MINORITY] community would be to consent to

participate in the programme? Why/why not? What additional reassurances might be needed?

10. If it was your job to figure out how to support people from [ETHNIC MINORITY] background to participate this research, what sort of initiatives / approaches would you try first, and why?

    a. Are there any methods would you recommend? Why?
    b. Are there any trusted voices (e.g. gatekeepers, opinion leaders) you would recommend Genomics England engage with? Why?

8.3. Appendix 3: Workshop topic guide

Introductions (10 mins)

Note to moderator: *Welcome participants back. Give everyone a chance to introduce themselves and meet each other. If observer is present, introduce them and let them meeting participants. Once this is done, explain:*

- The workshop will last for two hours
- We will take a short comfort break roughly halfway through the conversation
- We're really keen to learn, so I'd very much appreciate your open and honest responses
- As this is a group session, please could I ask everyone to be polite, respect the views of others, and give everyone the space to speak. If you are having trouble making yourself heard, please feel free to raise your hand using the Teams/Zoom function or message in the chat, and I will call on you. [Check that all know how to raise hand/use chat]
- We would like to record this discussion but only if all participants are happy with this. The recording is used to ensure we have an accurate record of the discussion for analytical purposes. With your consent we would also like to share this with Genomics England as they are keen to hear what you have to say directly. Do you have any concerns or worries about this? If you are happy, I'll start recording the session now. [Gain verbal consent]
- We may wish to use quotes in our report to help illustrate findings. Any quote would be anonymised – i.e., we won't attach your name to anything we quote. Are you happy for us to use anonymised quotes in our report? [Gain verbal consent]
- Basis are a company partner of a body called the Market Research Society and abide by their code of conduct. Participation in this discussion is completely voluntary and you are able to withdraw your consent to participate at any point in the process. This includes during this discussion, or up until the report is published at the end of March 2023. You also don't have to answer any question if you don't want to, you can just ask us to move on.

The agenda for today:

- First, we'll spend some time playing back what we heard during our previous interviews. During this part, we welcome your feedback on any points you think we have missed or misunderstood, or which need to be developed further.
- Second, I'd like to hear the groups thoughts on what the priorities should be for Genomics England, as they think about next steps for supporting members of the [NAME COMMUNITY] to participate in the Newborn Genomes Programme
- Third, and finally, I have some specific 'how might we' prompts that we would like your expertise on, focused on specific things that Genomics England could do to improve how it engages with the [NAME COMMUNITY]

Any questions before we start?

Module 1: Playback of findings from the listening phase (20 minutes)

Note to moderator:

- *Run through findings slides, illustrating findings by referring to what members of the group said during the interviews*
- *Give participants an opportunity to clarify / nuance / critique any findings that you present.*

FEEDBACK PROBES (ASK ON FINAL SLIDE):

- Anything missing?
- Any barriers that feel more / less relevant to the people from [ETHNIC BACKGROUND] that you work with?
- Any barriers that you think will be more / less prevalent among people from [ETHNIC BACKGROUND] that you work with?
- Any barriers that you think will be more common among specific sub-groups? If so, which ones and why?

Module 2: 'How might we…' (80 mins)

Note to moderator:

- *Begin by situating the ask in the context of what Genomics England will be doing next*
- *The goal is to give participants the space and opportunity to come up with ideas for how Genomics England should do this*
- *To help with this, we have provided a list of possible probes, - however, these are not a script – please exercise your own judgement in using these to unpack different aspects of how Genomics England should approach people from these ethnic backgrounds*
- *We suggest using the first 30 minutes as an open discussion brainstorming ways in which participants believe GE might address 'the ask', then following a 10 minute comfort break you can use the suggested probes to address (a) and (b) for 20 minutes, before focusing the last 10 minutes on (c)*

THE CONTEXT: moderators to talk through NGP status slides, so that participants understand where the programme is at and what will happen next.

THE ASK: How might Genomics England introduce the Newborn Genomes Programme in a way that best enables expectant parents from [ETHNIC BACKGROUND] to participate should they wish to?

Please work together to:

a) identify principles that will be important for any communications or engagement processes to align with
b) brainstorm key steps, processes or ways for engaging [NAME COMMUNITY] in the Newborn Genomes Programme at a local level
c) make recommendations to Genomics England

MODERATOR PROBES:

- How might we build **awareness and understanding** of the Newborn Genomes Programme among people from [ETHNIC BACKGROUND] living in the local community?
    - Overcoming language / literacy / vocabular barriers
    - Overcoming comprehension barriers to do with health research / genomics
    - Information channels / trusted voices

- How might we demonstrate the **trustworthiness** of the Newborn Genomes Programme to people from [ETHNIC BACKGROUND] living in the local community?
    - What needs to be put in place to make sure the programme is accountable in the event that things go wrong?
    - How can we maintain the transparency of the programme to members of the community?
    - How should we communicate uncertainties associated with our project (i.e. it's a research study – and studies, by their very nature, are uncertain)

- How might we make the people from [ETHNIC BACKGROUND] living in the local community **feel comfortable** learning about, discussing and making decisions about whether to participate in the programme?
    - Ensuring people feel comfortable discussing among friends and family
    - Providing discreate and secure ways of learning about the programme
    - Feeling comfortable in hospitals/medical settings

- How might we **support local community leaders** who work with people from [ETHNIC BACKGROUND] feel capable and confident having conversations about the Newborn Genomes Programme with members of their communities?
    - When should we engage?
    - How should we engage?
    - Who should we engage?
    - How to provide ongoing support?

- What would this process look like from the **perspective of an expectant mother / parents** from [ETHNIC BACKGROUND]?
    - Do the steps and processes you've identified address the likely questions or concerns that an expectant mother or parents might have?
    - When would/should they first hear about the Programme?

Close – 10 mins

Note to moderator:

- *Aim to leave enough time at the end for participants to share any closing views / remarks*
- *Gauge interest in participating in follow up research / conversations with Genomics England about the programme*