



CIBS IQ Research  
*Inclusion by Dialogue and Design*

# 100,000 Genomes Project

Black African and Black Caribbean Communities

A Qualitative Exploration of Views on Participation

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June 2018

## Acknowledgements

Dr Sophia Skyers, the author, would like to thank all of the focus group participants, event attendees and radio panel members for the invaluable contribution that they have made to informing this report and to shaping its recommendations. The participation of the community and the critical exchange of views is vitally important, and projects such as these cannot be undertaken without that active engagement. The author would also like to thank Can-Survive UK, BME Cancer Communities, Genomics England, and all of the healthcare professionals, geneticists, genetics researchers, and stakeholders from a range of organisations for sharing their knowledge, experience and insights so openly, and to Dr Rohan Morris for sharing his experience on ethnicity and access in relation to clinical research.

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## Executive Summary

### 100,000 Genomes Project

The 100,000 Genomes Project is aiming to sequence 100,000 whole genomes from approximately 70,000 consented NHS patients in the UK with all types of cancer, and rare diseases, as well as patients' family members, as these diseases are strongly linked to changes in the genome. The central pillar of the project is the creation of a genomics programme designed to bring benefits to patients. As part of its recruitment target, Genomics England has highlighted the importance of engaging with the UK's increasingly diverse black and minority ethnic population, and in particular, those with a family history of cancer, and/or rare diseases, who, for a variety of reasons, are often underrepresented in clinical studies and in clinical research. This includes those disease areas where black and minority ethnic people have a disproportionate risk.

### The purpose of the inquiry

Can-Survive UK and BME Cancer Communities, were commissioned by Genomics England to undertake a national community engagement programme with black African and black Caribbean communities. The organisations in turn commissioned Dr Sophia Skyers of CIBS IQ Research to work with them on the inquiry, and to produce a qualitative report. The purpose of the inquiry was an exploration of views about the 100,000 Genomes Project, and levels of awareness in black African and black Caribbean communities, and an exploration of views about the engagement of black and minority communities more generally from the perspectives of a range of stakeholders, and what it means for the 100,000 Genomes Project. This is part of a continuing programme of engagement with black and minority ethnic communities.

### The programme of engagement

This programme of engagement was carried out between March – June 2018, and was structured around six focus groups, three national events, two radio campaigns, and interviews with 20 key stakeholders. The inquiry centred on six geographical areas, Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich. The areas were selected on the basis of their varying black African and black Caribbean populations, and as representing a microcosm of England as a whole. In total 19 stakeholders took part in the enquiry and 55 black African and black Caribbean participants in the focus groups, and three national engagement events were held and two radio campaigns.

### Findings – Stakeholders:

The following themes emerged from the inquiry:

- a) **Ethnicity and an inclusionary approach:** A failure to be inclusionary in respect of groups already underserved in access to health and care services, and whose health outcomes are comparatively worse compared with the general population, is seen as further entrenching existing disadvantage. The failure to incorporate diversity into research to inform advances

in treatments is not in alignment with the broader principles of social justice, fairness and equity.

- b) Ethnicity is a social and administrative category, not a biological one. It is centred on approaches that seek to engage a representative sample of populations in order to understand the diverse genetic profiles of individuals spanning many continents, and where there may be common polymorphisms that are shared by all populations, as well as distributions that may be seen more frequently in populations that share a particular geographic ancestry. Therefore, research to inform treatments is based on genetic variations, not ethnicity.
- c) **Trust, judgements, stereotypes, assumptions, and cultural competency:** Trust in the objectives of the 100,000 Genomes Project and the process is seen as a potential barrier, as well as fears about how data are used, and the level of genetic literacy in the community. There are also organisational and attitudinal barriers that are seen to relate to lack of diversity in teams recruiting to the 100,000 Genomes project, and a lack of diversity among genetic counsellors. Moreover, barriers are also seen as resulting from judgement calls about community disinterest in scientific research, unconscious bias on the part of recruiters, and a lack of proactive investment in meaningful and authentic community relationships.
- d) **Organisational leadership, and institutional barriers and biases:** The framework for leadership does not support the enactment of equality and diversity. Therefore, organisational culture, systems, practice, and processes continue to remain impervious to it. As a result, organisations are not able to address the deeply challenging equality issues or capitalise on insights that could arise from a broader and more varied leadership base. The performance of organisations is therefore constrained in terms of having the ability to connect in meaningful ways with a broader constituency of interests.
- e) **Patient and citizen empowerment and disempowerment:** A transactional relationship exists between leaders and the communities they serve, including communities who are empowered and can influence and shape agendas. These may be empowered knowledge practitioner/patient communities, where the focus is on *'technical'* issues of access to specific treatments and not the social, cultural and economic process that also influence access. In this way social inequalities and ethnic inequalities in organisations and in research structures and processes are reproduced and reinforced.
- f) **What works or would work from the medical practitioner perspective:** Among the effective approaches to engagement identified were: genetics services representing and actually being part of the communities in which they work; finding a tangible story or lived experience through which to engage communities in research conversations, and the development of more sophisticated and nuanced equality resources and tools for practitioners that are of practical value in engaging communities in the shaping research of methodologies.

- g) Ensure that the 100,000 Genomes Project is aligned in a such a way as to influence regulatory NICE and commissioning pathways to inform clinical development programmes, and ultimately, clinical practice to the benefit of patients. There is currently no framework in place for this to happen and in the absence of this, talk about diversity and inclusion can be seen as hollow if there is no clear pathway for any patient to ultimately access effective novel treatments and therapies.

### **Findings – Focus group participants, awareness raising events, media campaign**

The following themes emerged from the inquiry through the focus groups, awareness raising events, and media campaigns:

- h) **Information and Resources produced by Genomics England:** With very few exceptions, the leaflets were described as too *‘technical’*, and *‘too wordy’* in their use of language, communicating a view that they are targeted at a more informed audience. They were also described as lacking clarity about what participation would mean in practice, and as excluding black people through a lack of visual representation. The videos were viewed as marginally more engaging but were also seen as excluding black people by failing to represent them visually.
- i) **Negative historical associations, and fear of sickness, disease:** A recurrent narrative related to negative historical associations in circumstances where black people have taken part in clinical research. This has given rise to fears that pivot on: anxieties about the uses to which data obtained will be put; fear of *‘experimentation’*; the potential for *‘ill treatment’*; the financial motivations of third parties such as pharmaceutical companies; fears about the *‘manufacture’* diseases using the bodies of black people, as well as fears of finding sickness. This is conjoined with fears about genomic medicine bypassing black people, and a lack of meaningful engagement with black people.
- j) **Safeguarding data and protecting the data of individuals:** There were concerns about the 100,000 Genomes Project in relation to pharmaceutical companies, commercial interests and individuals and this affected views about taking part. These were also fears expressed about gene manipulation to cause deliberate harm to black people, the security of individual data, and fears about the potential to criminalise black people via links to the Police DNA database. There were other concerns about insurance companies using genetic data to deny travel, life and other forms of insurance to individuals deemed *‘at risk’*.
- k) **The 100,000 Genomes Project and wider implications:** Individuals simultaneously hold contrary positions about scientific research, being interested and keen to engage on the one hand, whilst being held back by fears about the wider implications of taking part. This comes down to a lack of trust in the purpose and the process of clinical research. The fear of participation was for some, also linked to what non-participation would mean in terms of advancing knowledge about diseases that disproportionately impact black people, and a concern that non-participation would limit the construction of knowledge.
- l) The importance of inclusion in the 100,000 Genomes Project was also seen in the context of the wider benefits that could potentially be conferred on the future welfare and well-being

of family members such as children and grandchildren, as well as advancing medical knowledge which might not benefit individuals in the here and now but might benefit future generations and humanity as a whole. The medical needs of family were seen as something that would influence a decision to participate in some cases.

- m) **What works from the perspective of communities:** The need for messages about the 100,000 Genomes Project to be nuanced, targeted, and visually representative was seen as central, coupled with an understanding that one size does not fit all. This was seen as recognising that black communities do not represent a single unvarying set of interests and concerns. The development and dissemination of information through trusted sources and community venues, GP's TV and radio campaigns, through social media, and real-life case studies was also seen as important in engendering trust and confidence.

### **Conclusions, synthesis and recommendations**

The key findings are that there is correspondence between the views of stakeholders on barriers to participation, and the black communities who participated in this exercise. These barriers centre on historically grounded fears about engaging in scientific research, and the motives behind it. The way information about the 100,000 Genomes Project has been developed, the means through which that information has been transmitted, and the extent to which it is believed was also a fundamental barrier as it was seen as failing to engage and represent diversity. At the same time as being fearful about participating in scientific research, black communities also saw potential benefits of diverse participation for their families and for future generations and were therefore also concerned about genomic research leaving them behind.

The key findings also centre on institutional and individual impediments from a service planning and delivery perspective. These relate to; unquestioned assumptions about the way things are done in organisations; a lack of investment of time in community engagement; adopting a tick-box and/or ad hoc approach to diversity and engagement, and organisational decision-making becoming culturally bound within an equality vacuum due to a lack diversity. There were also community concerns about the extent to which benefits would actually accrue to black people, and concerns from stakeholders and community participants about what continued under representation would mean for the future of those not represented on the genomic database. In a similar vein, a critical barrier was seen to be the extent to which patients as a group are able to see the benefits of their participation, and the need for a clear articulation of the way the 100,000 Genomes Project will actually feed into and inform frontline clinical programmes and practice.

The following recommendations, which are grounded in the key findings are as follows:

It is recommended that:

1. Genomics England make the report available to organisations with key influence in clinical research and commissioning such as the National Institute for Health and Care Excellence (NICE), the Wellcome Trust, Public Health England, the Medical Research Council, Cancer Research UK, Genetic Alliance UK, Rare Disease UK, National Voices, the National Cancer Research Institute, and those involved in clinical research into cancers and rare diseases.

2. Genomics England seek to engage Public Health England, the Medical Research Council, the Wellcome Trust, Cancer Research UK, Genetic Alliance UK, Rare Disease UK, the National Cancer Research Institute, other stakeholders, and equality and diversity specialists, to lead the development of an equality impact assessment protocol, within the statutory framework set by the Equality Act, 2010. This should include appropriate guidance for assessments to be undertaken as a mandatory requirement in the conception, development and carrying out of sponsored clinical research, to ensure diverse representation and the more even distribution of its potential benefits.
3. While this project has focused on black African and black Caribbean communities, as part of a process of wider engagement, Genomics England should look to extending recruitment to the 100,000 Genomes Project beyond the current October deadline. It should continue to proactively engage black and minority ethnic communities more widely. Within the statutory framework set by the Equality Act 2010, this should form part of a coherent and on-going programme centred on the development of equality audited relevant and accessible information about the 100,000 Genomes Project, what participation involves, as well as awareness raising, and targeted events, developed with the black and minority ethnic voluntary and community sector, rather than one-off brief encounters.
4. Genomics England seek to ensure that the data and findings from the 100,000 Genomes Project are used to influence regulatory NICE and commissioning pathways to actually inform clinical development programmes and ultimately, clinical practice. This is to ensure that patients will actually benefit from the research knowledge generated, and that the wider aspirations of the 100,000 Genomes Project for patients with cancers and rare diseases are fully realised.
5. Alongside the collection of clinical data, the contribution of those participating in the 100,000 Genomes Project should be captured qualitatively. This should form an integral part of the process of reporting on outcomes from the 100,000 Genomes Project focusing on participants' experience from a social, emotional and practical perspective, alongside their individual reflections, in order to bring symmetry, balance and visibility to their experiences, alongside clinical findings, as part of an inclusive exchange to inform clinical research, policy and practice.
6. That the report be circulated to the High Commissioners of African and the Caribbean countries in the UK.

## 1. Introduction and background

1.1 **The 100,000 Genomes Project and engagement project deliverables:** BME Cancer Communities (BMECC) and Can-Survive UK, as part of the delivery of an engagement project on behalf of Genomics England, commissioned CIBS IQ Research to work jointly with them. The purpose of the project was to engage with black Caribbean and black African communities in England to explore levels of awareness and understanding about the 100,000 Genomes Project, and to explore views on Genomics England's information and resources through a series of focus groups. The purpose was also to organise and participate in three awareness-raising events and two radio campaigns across England, about the 100,000 Genomes Project. As an integral part of the research assignment, CIBS IQ Research was also commissioned by BMECC and Can-Survive UK to engage with healthcare professionals and community leaders to understand the 100,000 Genomes Project from their perspectives, their views on an inclusionary approach, and what it means for the future of personalised medicine.

1.2 **Structure of the report:** The report is structured in the following way: Section 2 briefly explores the 100,000 Genomes Project and sets the context for the focus on black and minority ethnic inclusion. Section 3, sets out the interrelated components of the project, the methodology for delivery, and explains why the six geographical areas, Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich, were selected. Section 5 presents the findings, synthesising the three components of the project, and the final section 6 brings together the key conclusions, and sets out a series of recommendations for Genomics England.

## 2. About the 100,000 Genomes Project

2.1 **Black and minority ethnic engagement and an inclusionary paradigm:** The 100,000 Genomes Project is aiming to sequence 100,000 whole genomes from approximately 70,000 consented NHS patients in the UK with all types of cancer, and rare diseases, as well as patients' family members, as these diseases are strongly linked to changes in the genome. The four main pillars of the 100,000 Genomes Project are: the creation of an ethically grounded genomics programme; the creation of an NHS genomic medicine service designed to bring benefits to patients; the fostering of new scientific discoveries and medical insights and acting as a catalyst for the development of a UK genomics industry. As part of its recruitment target, within an equalities framework and an inclusionary approach, Genomics England has highlighted the importance of continuous engagement with the UK's increasingly diverse black and minority ethnic population, and in particular, those with a family history of cancer, and/or rare diseases, who, for a variety of reasons, are often underrepresented in clinical studies and in clinical research. This includes those disease areas where black and minority ethnic people have a disproportionate risk.<sup>1</sup> As an

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<sup>1</sup> Sophia Skyers, Campbell Kerr and Pauline Johnson, Count Me In! Exploring the future of personalised medicine from bench to bedside, The Basil Skyers Myeloma Foundation, 2017  
Sophia Skyers and Vivienne Kendall Listen Up! Multiple Myeloma in Black Communities: An Unequal Risk Burden, The Basil Skyers Myeloma Foundation, 2015.

illustration, the largest prostate cancer trial that reported its results in 2016 enrolled very few black patients, despite the increase risk of prostate cancer in black men.<sup>2</sup> Furthermore, the recent global registration trial data for ASPIRE and ENDEAVOR which tested Kyprolis for refractory multiple myeloma revealed that black African and black Caribbean people, had very low rates of trial enrolment at 2.9% and 2% respectively, despite having double the risk of myeloma and a higher mortality rate.<sup>3</sup> Moreover, Asian women were significantly underrepresented in the recent PROCAS study on predicting the risk of breast cancer at screening, and black African Caribbean and black African women were also underrepresented.<sup>4</sup> This picture is mirrored in the 100,000 Genomes Project which, whilst experiencing no problems in recruiting black and minority ethnic people with rare diseases, has seen a major underrepresentation of black and minority ethnic people nationally in its cancer figures, and in particular, people of African Caribbean origin. In areas for example such as Greater Manchester which is home to large black and minority ethnic populations the following table illustrates this:

Participation in 100,000 Genomes Project <sup>5</sup>			
Ethnic Origin	% In Study	% Nationally	% Greater Manchester
White British	85	86	66.7
Pakistani/Bangladeshi	4.2	1.8	9.8
Indian	2.5	2.1	2.3
Black Any	0.8	-	8.6

2.2 At the axis of the planning and delivery of healthcare and other public services are the principles of ‘equality’ and ‘inclusion’. These principles integrate a focus on black and minority ethnic communities in relation to service access, and in relation to health outcomes where they are failing to keep pace with the general population.<sup>6</sup> The first samples for sequencing the human genome are being taken from patients living in England and alongside this, discussions are in progress in Scotland, Wales and Northern Ireland about their potential future involvement. In recent years, the focus on equality and inclusion has begun to encompass nascent biomedical technologies and the shift towards more targeted therapies as part of a move towards personalised medicine.<sup>7</sup> The Human Genomes Project, which mapped the entire human genetic code, demonstrated that in biological terms, humans share 99.9% of their DNA and that the remaining 0.1% cannot be attributed to race. The same conclusion was also reached by studies in

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Rose Thompson, Hear Me Now: The Uncomfortable Reality of Prostate Cancer in Black African and Black Caribbean Men, 2013.  
<sup>2</sup> Freddie Hamdy et al, 10 Year Outcomes after Monitoring, Surgery, or Radiotherapy for Localized Prostate Cancer, New England Journal of Medicine, October 13, 2016: 375: 1415-1424.  
<sup>3</sup> A.K Stewart and Vincent Rajkumar et al.; Carfilzomib, Lenalidomide, and Dexamethasone for Relapsed Multiple Myeloma, New England Journal of Medicine 2015: 372:142-152 and Meletios A, Dimopoulos, Phillipe Moreau, et al., Carfilzomib and dexamethasone versus bortezomib and dexamethasone for patients with relapsed or refractory multiple myeloma (ENDEAVOR): a randomized, phase 3 open-label, multicenter study, Lancet Oncol. 2016; 17:27-38.  
<sup>4</sup> D. Gareth Evans and Anthony Howell, Can the breast screening appointment be used to provide risk assessment and prevention advice? Breast Cancer Research (2015) 17:84.  
<sup>5</sup> Taken from presentation delivered by Professor Gareth Evans, Professor of Genomic Medicine, Manchester, Manchester BME Genomics Event, organised by Can-Survive UK, Monday 30, April  
<sup>6</sup> A refreshed Equality Delivery System for the NHS, EDS2 – Making sure that everyone counts. November 2013, November 2013 <https://www.england.nhs.uk/wp-content/uploads/2013/11/eds-nov131.pdf> Accessed February 6, 2017.  
Department of Health, The NHS Outcomes Framework, 2016 – 2017.  
<sup>7</sup> Lock M, Nguyen VK. An Anthropology of Biomedicine. Chichester: Wiley-Blackwell, 2010.  
Steven Epstein, Inclusion: the politics of difference in medical research, The University of Chicago Press, 2007.  
Catherine Bliss, Race Decoded: The Genomic Fight for Social Justice, Stanford University Press, 2012.

previous decades, using a variety of genetic and molecular methods.<sup>8</sup> The terms race and/or ethnicity in the context of clinical research do not thus denote inviolate biological naturally occurring categories, rooted in the genetic script of individuals or groups sharing particular physical and/or social attributes, but are imprecise, socially constructed and self-assigned classifications.

2.3 The case for the application of socially constructed definitions of race and ethnicity in the context of 100,000 Genomes Project is an inclusive agenda. It is important for reasons of ethics which is one of the key stated hallmarks of the project, and because widening trial participation can potentially bring benefits in terms of further enlightenment and acuity in understanding more about disease aetiology and disease pathogenesis. This is by recruiting from a diverse population pool, where the particular experiences of groups and individuals also influence their health and health outcomes. An inclusionary approach can potentially generate ideas for service design and accessibility, and can add to the existing armamentarium of therapies, and therefore inclusion is fundamental to the future of personalised medicine. It is important however to develop a critical appreciation of what is meant by race and ethnicity in the context of clinical research, and how these concepts are being translated in the 100,000 Genomes project. This is because as concepts, ‘*race*’ and ‘*ethnicity*’ are often employed uncritically in scientific research, even though their pedigree is a long, variegated, and indeed, contested one. A more critical reflection is therefore necessary to examine how meanings and interpretations of race and ethnic categories will: potentially infuse clinical research and practice and social and health policies; what this implies in terms of the way in which people are cared for and the way in which services are provided; what this means in terms of understanding some of the precursors of disease, and what this means in terms of new and more effective treatments. Indeed, reflecting on the way in which knowledge is curated and the assumptions underpinning the construction of knowledge is important to diversity in clinical research, as well as in guarding against shaping views about people from black and minority ethnic groups in ways that might unwittingly stereotype patients, or reinforce existing prejudices.

2.4 **Race and ethnicity as dynamic socially constructed concepts:** As imprecise, self-assigned and socially constructed concepts, what we understand by race and ethnicity is dynamic, historically contingent, and therefore changes over time. This dynamism has included seismic shifts in how the terms are defined and interpreted, including within the last 20 years. Added to variations in definition and interpretation over time are also variations by country.<sup>9</sup> As self assigned artificial constructs, it is also the case that how individuals self identify, or whether they choose to identify at all, also changes with time as individual notions of identity and the expression of it change.<sup>10</sup> There

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<sup>8</sup> Foster MW, Sharp RR. Race, ethnicity, and genomics: social classifications as proxies of biological heterogeneity. *Genome Res* 2002; 12:844-850, also see Lewontin R C. *Evol Biol.* 1972; 6:381–398.

<sup>9</sup> To illustrate these points further, the UK Population Census has a number of ethnic categories. This includes the white group and the black group, both of which are defined principally by colour. The South Asian group by contrast is defined not by colour, but by reference to an entire continent. The Chinese group is defined by reference to an ethnicity and included in the overall Chinese category is the culturally distinct Vietnamese group. This is a radical departure from the 1991 UK Population Census, which as illustrated by the Office of National Statistics, *A Guide to Comparing 1991 and 2001 Census Ethnic Group Data*, which had different categories of ethnicity in the two periods, and different questions were asked in England, Scotland, Wales, and Northern Ireland during this same period. In terms of other variations by country, in the UK, the Asian and Chinese groups are distinct Census categories whereas in the US, the Asian Census category includes the South Asian and Chinese population in one group.

<sup>10</sup> See for example JRF and Manchester University, *Dynamics of Diversity: Evidence from the 2011 Census*, ESRC Centre on Dynamics of Ethnicity, March 2014 which, through anonymous records linking responses to 2001 and 2011 Census, was able to track how individuals express their ethnic identity across time, with significant proportions choosing a different ethnic group in 2011 to the one they selected in 2001.

is an added layer of complexity in practically applying broad race and ethnic categories given that the 200,000-year history of humans has been one of constant migration, cultural exchange, and cultural fusion. Therefore, infinite diversity is not reducible to a few ascribed groupings that have been assigned an official governmental imprimatur. They cannot and were never intended to accurately account for identity and experience either at a group level, or at an individual one, and where ancestry spans more than one continent, as is the case for every one of us.<sup>11</sup> This has important implications in terms of the way race and ethnicity potentially shape and inform genomics research and practice, with all the methodological constraints this implies for data collection and comparison; comparisons over time; comparisons between continents, and critically, how patients self-identify, as this project has also revealed, and how aggregate data will inform personalised medicine and ultimately, patient care.<sup>12</sup>

**2.5 The relevance of ancestry and biosocial variables:** While race and ethnicity are not biological categories, the terms are nevertheless valuable in medical research as broad social constructs. They add greatly to our understanding of patterns of inequality and health disparities, as well as inequalities in recruitment and participation in clinical research. These patterns of inequality are based on shared social attributes and individual and collective experiences that have biological consequences. Therefore, understanding these patterns of inequality is critical to the framing, understanding, and contextualizing of risk and health disparities, and to personalised medicine. It is also important to be clear that while some people in continental groups have particular polymorphisms, these frequencies do not correspond, map onto, or align with socially constructed policy determined race and ethnic categories.<sup>13</sup> It is continental ancestry that has relevance and nowhere is this seen with greater clarity than for example in the Human Leukocyte Antigen (HLA) typing that is used to match stem cell donors to patients. HLA is a protein or marker found in most of the cells in the human body. The immune system uses HLA markers to determine which cells belong in a particular body and which do not. HLA matching is important in allogenic bone marrow transplantation to prevent graft rejection and other serious complications. Ancestry is pivotal to this because patients are more likely to find a match among potential donors from their own ethnic group so black and minority ethnic patients in the UK for example, face more obstacles in finding suitable donors. This is because of their smaller numbers in the donor pool, and because black and minority ethnic people are under represented on the donor registry. Moreover, black and minority ethnic patients who are of dual heritage, for example, African and European or other ancestry, have a rarer HLA variation and therefore have an even smaller chance of finding a suitable stem cell donor.

**2.6** As researchers begin to formulate a view on the complex relationship between our genetic endowment and what happens to us during the life course through understanding more about the

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<sup>11</sup> David Reich, *Who we are and how we got here: New science of the human past*, Oxford University Press, 2018

<sup>12</sup> A patient from Jamaica for example, who has Indian or Chinese ancestry, will share an identity as an African Caribbean, or black Caribbean. Therefore, group based notions or probabilities should not to be employed in making judgments about individual patients on the basis of group membership because individuals do not confirm to group assumptions.

<sup>13</sup> Karama C. Neal, *Use and Misuse of "Race" in Biomedical Research*, *Online Journal of Health Ethics*, 5(1) <http://dx.doi.org/10.187585/ojhe.0501.08>.

Catherine Lee, "Race" and "ethnicity" in biomedical research: How do scientists construct and explain differences in health? *Social Science and Medicine*, 68 (2009) 1183 – 1190.

interaction of complex biosocial variables: genetics and genetic inheritance; epigenetics and epigenetic inheritance; environmental signals; the contours of response, and response variation and so forth, a different set of questions arise from the myriad factors that may correlate with the social categories of race and ethnicity, and other social groupings, and which have implications for the collection of epidemiological data, and the future of personalised medicine.<sup>14</sup> This is particularly important given the underrepresentation of black and minority ethnic communities in NHS Clinical Genetics Services, and their underrepresentation in clinical trials and clinical research, including in those disease areas, for example, multiple myeloma and prostate cancer where, as already stated, black people have a disproportionate incidence of diagnosis, a higher mortality rate, and are under-represented on the Genomics England database. Moreover, as is the case with the population generally, the trajectory of disease does not follow one clinical course but many.

2.7 A discussion of intra-group difference is also germane to the 100,000 Genomes Project in that T-cell malignancy, one of a group of aggressive non-Hodgkin lymphomas is higher in the black population, particularly black women. There is also evidence for example of a disparity in the incidence of Hodgkin lymphoma and mature B-cell malignancies in the South Asian population, with a disproportionately higher incidence among men in the South Asian group as a whole, and within that group, a significantly higher proportion among Pakistanis compared with Bangladeshis.<sup>15</sup> Thus, as well as engaging with and increasing recruitment of black and minority ethnic people, the 100,000 Genomes Project also seeks to be cognisant of inter and intra-group cancer and rare disease evidence, albeit limited, within a socially responsible use of ethnic categories. While this commissioned project has specifically targeted black African and black Caribbean communities, it should be seen very much as a precursor to wider engagement with black and minority ethnic communities given, as already discussed above, inter-group and intra-group variations in the incidence and diagnoses of certain diseases, and under representation within black and minority ethnic groups generally in clinical research. The next hurdle will be annotation, that is, interpreting the meaning and importance of those differences that are important, and those that are natural harmless variations between people.

### 3. Purpose and approach to conducting the study

3.1 **The selection of the geographical areas in England:** The purpose of the study was an exploration of views about the 100,000 Genomes Project, and levels of awareness in black African and black Caribbean communities. The project also explored the issues of engagement of black and minority communities more generally from the perspectives of a range of stakeholders. The project focused on six geographical areas, Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich. The areas were selected on the basis of their varying black African and black Caribbean populations, and as representing a microcosm of England as a whole. They included therefore, areas of significantly high black population, for example Leeds, and other areas such as Nottingham that, as well as having high black populations, also have among the fastest growing mixed populations outside of London. They also included areas such as Ipswich, home to a growing black African and

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<sup>14</sup> Epstein, Steven, Op. Cit. 6.

Marmot, Michael, *The Health Gap: The Challenge of an Unequal World*, Bloomsbury, 2015

K Dimopoulos, P Gimsing and K Grønbaek, The role of epigenetics in the biology of multiple myeloma, *Blood Cancer Journal*, 2014, 4.

black Caribbean population, and home to the largest black and minority ethnic community in Suffolk but due to its relatively smaller population size, is an area that is often neglected as a focus for research.

3.2 The deliverables of the project were: a series of 7 focus groups with black African and black Caribbean participants; a series of qualitative interviews with key stakeholders drawn from among the scientific community, healthcare professionals, and community representatives; two urban radio media campaigns, and three national events. These are outlined in the table below:

Qualitative Exploration	Campaigns and Events
<p><b>Focus Groups:</b> Recruitment of black African and black Caribbean people, including those with a personal and/or family history of cancer or rare disease in Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich, to a facilitated focus group in each area (7 focus groups in total) centred on awareness and an assessment of Genomics England information and resources in respect of the 100,000 Genomes Project.</p> <p>Within the 6 focus groups x 55 participants in total, an exploration of the views of black African and black Caribbean people on the 100,000 Genomes Project, and their views about participation in clinical research.</p>	<p><b>Media Campaigns:</b> Two radio campaigns in partnership with 97.5 Kemet FM, a popular licenced urban radio station in Nottingham, and Legacy FM, a licenced urban radio station in Manchester, with experts from the scientific community, Genomics England, and black and minority ethnic patient and advocacy organisations.</p>
<p><b>Stakeholder Interviews:</b> 19 in-depth stakeholder interviews with clinical geneticists, genetic counsellors, genetics researchers, and community leaders with an interest in health and care services on widening participation in the 100,000 Genomes Project from their perspectives.</p>	<p><b>National Events:</b> The delivery of three events in areas with significant black and minority ethnic populations, that is, one each in Manchester, Sheffield, and West Bromwich, with experts from the scientific community, Genomics England, and black and minority ethnic patient and advocacy organisations.</p>

3.3 The recruitment of community participants to the focus groups and national events, and for the interviews with stakeholders, was carried out using a purposive recruitment approach via organisations, active working networks, and through a process of snowballing. This included patient and advocacy organisations providing a range of community based social, health, care, cultural, and recreational services, and faith based organisations. The participants were drawn from various Caribbean Islands, and from various African countries. The stakeholders drawn from among healthcare professionals, geneticists and genetics researchers were identified via organisational leads provided by Can-Survive UK, BMECC, and the Basil Skyers Myeloma Foundation, and through existing contacts and snowballing. They included geneticists who recruit people with rare diseases and inherited cancers as part of the 100,000 Genomes Project, those working with genetic conditions that predispose to malignancy, and rarer conditions that are not explained by existing genes and who are interested in family history, and genetic counselors delivering clinical genetics counseling services, working with people with family a history of cancer or rare disease. As well as the qualitative component, the national engagement events were held in Manchester, Sheffield and

West Bromwich, and community radio shows in Manchester and Nottingham. The radio campaigns worked through contacts within licensed urban radio stations who engage with local and national black African and black Caribbean audiences. The radio shows and the national events both included geneticists, researchers and genetics counselors engaged with the 100,000 Genomes Project, representatives from Genomics England, and patient and advocacy organisations.

3.4 The components of the project formed part of an integrated and coherent approach to engaging with a wide audience, communicating information about the 100,000 Genomes Project, and obtaining a wide range of views. The approach was designed to augment and to triangulate the findings. As the engagement proceeded, it became necessary to carry out more intensive work to ensure that the black African community was fully represented, and this was carried out using a refined purposive approach through African-led organisations and networks. The findings, which are set out on a thematic basis, are discussed below.

## 4. Discussion of findings

### a) Interviews with stakeholders

4.1 The themes arising from the interviews with stakeholders are summarised below and are explored more fully in the ensuing paragraphs:

- a) Ethnicity and an inclusionary paradigm
- b) Trust, judgements, stereotypes, assumptions, and cultural competency
- c) Organisational leadership, and institutional barriers and biases
- d) Patient and citizen empowerment and disempowerment
- e) What works or could work from the medical practitioner perspective:

4.2 **Ethnicity and an inclusionary paradigm:** A recurring theme across the interviews with stakeholders was the notion of an inclusionary approach to the 100,000 Genomes Project as central to its overall success. This was seen in terms of the potential to inform the future of personalised medicine, using the genome as a prism through which to develop a greater understanding of populations, continental ancestry, and different polymorphisms both within and across populations. The importance of inclusion in relation to the 100,000 Genomes Project was therefore seen in terms of it reflecting the whole of humanity, and as being aligned with broader principles of social justice, fairness, and equity. An issue highlighted by stakeholders and practitioners was that, in the absence of an ethnically broad base for constructing knowledge, certain polymorphisms or allele frequencies might not be identified. This was seen as being potentially negative in its impact on society as a whole by placing limitations on our overall understanding of the aetiology of all cancers and rare diseases, and our understanding of disease pathogenesis: including but by no means being limited to those diseases that disproportionately impact black African and black Caribbean people. Dr Simon Ridley, Director of Research at Myeloma UK talked about the organisations' aspirations for its patient group in the context of the 100,000 Genomes Project in this way:

*'I think when looking at rare diseases, it is important that we have a broad background of people from different heritages, so we capture the diversity of the human genome. We want research to go beyond that and if there are some associations between certain populations*

*and particular diseases, such as sickle cell or myeloma which disproportionately affects black African and black Caribbean people ... We are supportive of the 100,000 Genomes Project and would be pleased to see data that benefits myeloma research and more importantly, myeloma patients' (Dr Simon Ridley, Director of Research at Myeloma UK).*

4.3 An inclusionary approach was thus seen as holding benefits in terms of potential future personalised treatments being justifiably extended to a diverse population, rather than constructing knowledge from a limited pool to inform treatments that are then extended to diverse treatment populations. Moreover, a failure to be inclusionary in respect of groups already underserved in access to health and care services, and whose health outcomes are comparatively worse in relation to the general population, was seen as further entrenching existing disadvantage precisely by failing to incorporate diversity in informing advances in treatments based on genomics. Dr Julian Barwell, Clinical Genetics Lead, University of Leicester, spoke about the importance of an inclusionary paradigm and the implications of incorporating diversity. This was in terms of understanding the potential changes in DNA that could be disease causing and identifying differences and changes in the DNA sequence that might be seen in particular parts of the population. The failure to take account of diversity was therefore expressed by Dr Barwell in the following terms:

*'The implications of not being represented is that we won't answer the questions that are relevant to those patient groups. Are, there common ancestry genes that are common to those people? Why are black men developing prostate cancer? So, there is a medical problem there but from a more molecular perspective, when we see a variant, understanding whether it is disease causing or not. Then there is an ethical issue in that genetics has underserved these populations' (Dr Julian Barwell, Clinical Genetics Lead, University of Leicester).*

4.4 A theme that came through prominently was that ethnic diversity in the context of the 100,000, Genomes Project is not about stratifying populations according to administrative self-assigned and socially constructed race and/or ethnicity categories that are historically contingent, and country specific. Rather, in terms of the 100,000 Genomes Project, ethnic diversity is seen as conforming to continental ancestry. In that sense, inclusion is regarded as important given that the history of humans has been one of constant migration, and therefore, attempting to capture some of this infinite diversity is likewise seen as important to the project in terms of potential universal benefits.<sup>16</sup> This is centred on approaches that seek to engage populations in order to understand the diverse genetic profiles of individuals spanning many continents, and where there may be common polymorphisms that are shared by all populations, as well as distributions that are seen more frequently in populations that share a particular geographic ancestry. This effectively means learning more from the data that is being collected. Professor Gareth Evans, Manchester Centre for Genetics explained it in this way:

*'The implications of this are that nearly all of the research has been done in the white population and that is where most of the applicability will be so, we will have missed things*

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<sup>16</sup> Reich David, Who we are and how we got here, Oxford University Press, 2018.

*that will have been identified in other populations. The danger is that there will be less research relevant so particularly when we are looking at common genetic variants and polygenic risk scores, those scores will be less good as they will have less validation in populations that have different distributions. Diabetes is one example and myeloma is another....It should be about gene or the genetic change, which means that the drug is effective as these genes are common in all populations but might be more prevalent in certain populations but the treatment should be based on the tumour genetic abnormality. It is genes and treatment rather than race-based treatment, and it is down to badly used knowledge to try and turn it into something else. It is erroneous to paint an entire group of people with a particular category where you are saying this won't work whereas it should be based on your genetics rather than inaccurate race and ethnicity categories' (Professor Gareth Evans, Medical Genetics and Cancer Epidemiology, St Mary's Hospital, NHS Foundation Trust, Manchester Centre for Genetics Medicine).*

4.5 A number of issues were highlighted concerning the ethnic categories used in the 100,000 Genomes Project. The categories used are data driven categories based on the government Census and within those categories, the collection of ethnic data, and its articulation in the 100,000 Genomes Project is often undertaken in an improvised way because ethnicity is an elastic concept, and all ethnic groups cannot be accounted for. This raises some concerns about veracity that Dr Freyja Docherty explained in this way:

*'What we go on is when we have the person in the clinic I fill in a questionnaire and the boxes are quite limited actually and people tick those. What we have is like a drop-down list. To be honest, if I say to someone: "how would you describe your ethnicity?" and that is not on the list, then they have to pick what I have asked them to choose between. There is no free text option there is only a box. So, I say in what why does this hamper analysis? What is really interesting is they have nothing for people who are central Asian. There are certain assumptions in ethnicity and there are some tight margins and there is not a lot of manoeuvre in those categories really' (Dr Freyja Docherty, GMC Genetic Counsellor, Sheffield Teaching Hospitals).*

4.6 **Trust, judgements, stereotypes, assumptions, and cultural competency:** The matter of gaining the trust and confidence of black people was seen by stakeholders as a potential barrier within the context of discussions about genetics, specifically, how the data are to be used, the way the results will be shared and with whom, concerns about what participation might mean for other family members and myriad other fears. There were also perceived structural, organisational and attitudinal barriers from the stakeholder perspective that were seen as impacting participation. A barrier highlighted by some stakeholders was the lack of diverse representation in project teams seeking to recruit to the 100,000 Genomes Project, a lack of genetic counsellors from black and minority ethnic backgrounds, an underestimation of the level of resource required to recruit, and an underestimation of the time commitment needed to proactively engage in discussions with communities about the Project. Indeed, effective engagement was seen by some stakeholders as requiring a unique type of investment in community relationships, as well as the need for recruiters to develop the necessary skills. There has been pressure to recruit swiftly to the 100,000 Genomes Project and with limited resources and time allocated to patient and public involvement, it can be

seen as 'easier' to recruit those who are 'easiest' to recruit. Julie Atkey, Co-operational Lead and Genomics Education and Training Manager, Yorkshire and Humber Genomic Medicine Centre, expressed this in the following way:

*'It appears that the majority who have engaged so far have been white British and a lot of the meetings we have attended have not been represented by minority groups. Now why are they not engaged? There appear to be many barriers to accessing these groups to raise awareness. The opportunities are more limited and with the limited resources we have we go for engaging the biggest numbers. We have held awareness raising events and been in schools etc but the main groups that we have targeted in doing that have not been the ethnic groups so we know the amount of time we have dedicated to those groups has been limited. Prior to this secondment I was a scientist in the lab most of the time so doing this had been a real eye opener for me. This is something that we all need to learn from...I feel very conscious that as a project team we must look very white and not really representative of the community as a whole. I think that is a barrier and we need to be cognisant of the factors, some of which we will be aware of and some of which we will be clueless about' (Julie Atkey, Co-operational Lead and Genomics Education and Training Manager, Yorkshire and Humber Genomic Medicine Centre, St James's University Hospital).*

4.7 There were many other potential barriers identified by stakeholders, one of which, pivots on an assumption that black and minority ethnic people are more likely to be disinterested in participating in scientific research and clinical studies, and that they will therefore be more likely to say no. This particular issue is also seen as melding with genetic literacy in black and minority ethnic communities in terms of understanding what a genome is, and what the 100,000 Genomes Project means for them in practical terms. In these circumstances, it can therefore be seen as easier not to make an approach because of prior assumptions about the ability to understand, levels of education, language proficiency, and so forth that might mean a requirement for more dedicated time, and/or the use of translators when seeking informed consent. Added to this is that community engagement is seen as being outside the experience and comfort zone of some organisations and/or people who are employed within the research community. This can be exacerbated where there are not sufficient organisational inroads to the community, where there are perceived issues of cultural alignment with the community they are seeking to engage, and which are then negatively reinforced by a lack relevant diversity training. In this way, recruiters may consciously and unconsciously contribute to underrepresentation through the judgement calls that they make about 'if' an approach should be made, 'who' to approach, and whether it is 'worth it'. The following remarks made by Vivienne Parry, OBE, Head of Engagement, Genomics England, and Naz Khan, Principal Registered Genetic Counsellor confirm this view:

*'So, I think absolutely yes. So, let me preface this by saying that the NHS are incredibly concerned to have equity of access in genomics and I think one of the issues is historical, and which remains is the view that a black man is less likely to say yes to inclusion in a clinical trial so there is no need to bother asking in the first place. In my experience, that thinking is quite prevalent. There is no suggestion where people of Caribbean origin have a sick child, that they are asked less than the population generally to take part in a clinical trial. Cancer however is a different matter it is the case that black and minority ethnic people are asked*

*less often because it is assumed that they will say no. I worked a lot in organ donation and there is an assumption that the people are not going to be interested so there is little point in asking in the first place' Vivienne Parry, OBE, Head of Engagement, Genomics England).*

*'There are not enough genetic counsellors from black and minority ethnic backgrounds and I am the only one in Manchester and they also come from middle class backgrounds and have not been exposed to communities. The training they get is not sufficient and if you are a nurse and work in a middle class hospital and then go and work in East London, it is hard not to make judgements and there is sometimes a fear...I don't think there are enough professionals from ethnic backgrounds and we all do corporate mandatory training and we all do diversity training about treating people fairly but I think there needs to be a bit more' (Naz Khan, Principal Registered Genetic Counsellor, Manchester Centre for Genetics Medicine).*

**4.8 Organisational leadership, and institutional barriers and biases:** Despite changing demographics, migration, and global connectivity which has created an imperative for organisations to transform and to embrace diversity, organisations are often seen as impenetrable or resistant to change. The notion of diversity can become locked in at a rhetorical level as structural and institutional barriers mesh with and are mediated through issues of cultural competence and cultural alignment, as well as ideas of leadership and what constitutes good leadership, and the priorities for resource allocation. Indeed, leadership is not always seen as supporting multiple identities and different ways of seeing and doing. A number of the stakeholders that we spoke with pointed out that where organisations are culturally bound in this way, and where the framework for leadership cannot support the enactment of diversity, organisational culture, customs, practice, systems and processes will continue to remain impervious to diversity. Moreover, where recruitment to leadership roles takes place through restricted networks those who are part of those restricted networks have preferential access to leadership roles by default.

**4.9** There is thus, little space for organisations to address the deeply challenging issues that result from a failure to embrace diversity, or to recognise and capitalise on insights that can arise from a broader and more varied leadership base. In this vacuum, assumptions can be made by decision makers that serve to compromise access to the involvement of black and minority ethnic groups in research, treatments, service planning, service delivery and so forth. In other words, entrenched bias, albeit unconscious, means that decision makers and leaders may be unable to see that they are acting in ways that are indirectly or directly exclusionary. They are not able to and do not have to question their norms and assumptions as they see them as neutral, and therefore fail to understand the social processes through which they work and the organisations that they are a part of, and the negative impact from an equality perspective. This in turn constrains the performance of organisations, and their ability to engage with some of the more provocative questions that might connect them with a broader constituency of interests and enable them to move towards serving all populations in a meaningful way. In that sense, it is not a conscious choice of operation to exclude, but a lack of understanding. Rosemarie Finley, Chief Executive of Myeloma UK, and Dr Freyja Docherty talked about institutional impediments, the need for transformation through positive action and its importance to the 100,000 Genomes Project in this way:

*'So, if you think about system and processes and how they are not set up to be engaging, it comes down to people because people are in charge of the systems and processes and write them and carry them out but those people who have written the processes, and policies, are very unlikely to be from a background of a minority group. So, those people do not have an understanding of the needs and expectations of the needs of people in a society that has ethnic minorities so there are blind spots. They are not inclusive, and they are not ensuring that the risk and all the factors involved in the research are looked at from the perspective of the individual minority group. They make assumptions that are often wrong. It assumes a lot of things and those assumptions are likely to be inaccurate for anybody who sits in a minority group. It is a lack of alignment and knowledge as they don't know what they don't know as they don't understand the social constructs for a group of people that they have never engaged with or understood...I think representation is crucial to the 100,000 Genomes Project because it will enable us to have the evidence to see that different patients need a stratified approach and leading to an individual approach, and it will improve outcomes. You have to have positive action to ensure that it is inclusive and that you have got the full diversity that is required for the population of the country.'* (Rosemarie Finley, Chief Executive, Myeloma UK).

*'I don't know how much it is on the side of communities not engaging or if it is on the side of certain doctors not referring people from those communities and thinking they won't be interested but all I see is the people who have been referred to me so, I don't have a say in who is sent to me. I think also in what is really interesting is Genomics England, don't provide any translated information sheets and they have been requested and they said that is to the cost of your own department. They said if you want them, you've got to pay for them which for the NHS services, it's not easy to get money to pay for them. In a multiracial society it is not what you would expect'* (Dr Freyja Docherty, GMC Genetic Counsellor, Sheffield Teaching Hospitals).

4.10 The impediments to diversity were not therefore seen by stakeholders as solely a lack of willingness on the part of black and minority ethnic populations to engage, or lack of capacity or understanding, but were seen also in terms of the ways in which organisations, groups within organisations, and individuals, can unwittingly exclude on the basis of taken for granted norms and assumptions. This is therefore an issue of capacity and understanding within organisations, albeit one that is not widely recognised. In that sense, the impediments to change are seen as resulting from existing local institutional arrangements that encumber national diversity initiatives.<sup>17</sup> Marcella Turner, Chief Executive and Founder of Can-Survive UK put it in this way:

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<sup>17</sup> This is borne out by a 2014 and 2018 report, which provides some evidence of Board composition in the NHS being unrepresentative of black and minority ethnic communities, Kline, Roger, The snowy white peaks of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England, Middlesex University, 2014. A similar situation prevails in the voluntary sector in that in relation to its board recruitment practices that have the effect of excluding black and minority ethnic communities. See for example, a comprehensive report by the Charity Commission entitled, Taken on Trust, November 2017 the awareness and effectiveness of charity trustees in England and Wales. The report found that 92% of charity Trustees are white and two thirds are male, a situation that is exacerbated by the fact that the majority of charities practice recruiting Trustees by word of mouth or personal recommendation through existing networks which impedes the effectiveness of the sector.

*'I work within the voluntary sector and am involved in various Cancer Boards, committees and groups. I had seen information about the 100,000 Genomes Project in local meeting papers but was not 100% sure what it was about and at those local meetings, no emphasis was ever made for the need for more BME people to connect with the national project being run by Genomics England, so the messages do not always reach. I don't know if the matter was discussed at meetings I may not have attended. The important thing is that we need to be around that table to highlight the gaps or they are missed as decision makers do not necessarily always look at things from a BME perspective' (Marcella Turner, Founder and Chief Executive Officer, Can-Survive UK).*

4.11 The impediments to diversity were also seen in the context of trust between organisations. This was based on experiences where black and minority ethnic community organisations felt they has been 'used' by mainstream agencies to 'tick their boxes', or to 'get intelligence' to advance their own interests, and in that sense were insincere. In those circumstances, unless black and minority ethnic organisations had established mutually trusting relationships with external partners, they said that they would be reluctant to engage unless the terms were clearly specified, and preferably in writing. Clem Turner, Chairman of the Caribbean and African Community Health Project Support Forum, Ipswich, cited his organisations' experience, as evidence:

*'The question that I'll be getting is what happens next? For me that is something that I'm not looking forward to dealing with because I don't really know what happens next...This is no reflection of you (the interviewer), but we've worked with several organisations over the last eight nine years and we've invited different organisations to come in. Let me rephrase that, we've actually opened the doors for organisations to come in and what they do they come in and they make promises, and then when they get what they want, you don't see or hear from them again you know, and that is where the distrust comes from. I'll give you an example, we did a project around dementia with the Council and they gave us a little bit of funding so what we did, we did a six-week course on dementia then we submitted the report. They then take the report and then branch it out to somebody else and didn't include us and we then become very sceptical of inviting people in unless they are going to put down in front of us, this is what they outcome is going to be, this is where we are going. We tend to be feeding people with ideas and then they'll tick their boxes' (Clem Turner, Chairman of Caribbean and African Community Health Project Support Forum, Ipswich).*

4.12 **Patient and citizen empowerment and disempowerment:** The lack of black and minority representation in clinical studies is also seen to exist because leadership is a transactional relationship between those who lead internally, and those who follow and/or play a supportive external role, receive services and so forth, or who are empowered and can influence and shape agendas. Where the follower and/or support base, like the leadership, is not ethnically diverse, and when minority voices are seldom heard, the leaders may continue to mirror the expectations of a follower/support base, whose norms are in alignment and who may also be resistant to change. These may be empowered knowledge practitioner/patient communities, where the focus is on 'technical' issues of access to specific treatments and not the social, cultural and economic process that influence access. In this way social inequalities and ethnic inequalities in organisations and in research structures and processes are reproduced and reinforced. Professor Frank Chinegwundoh

MBE, Consultant Urologist, Barts, spoke about resistance to change and the imperative for organisational and institutional change in this way:

*'They don't want challenge and are not ready for that, but the more people make the challenges, eventually, things have to change. If there is no challenge, there is no change. You have to challenge, the next time and the time after that, even though it means that it will be very hard work. If you keep knocking at the door, I may not get onto the board of these major organisations as a Trustee or a non-exec, but it might make it easier for someone who comes along subsequently' (Professor Frank Chinegwundoh MBE, Consultant Urologist, Barts Health NHS Trust).*

**4.13 What works or could work from the medical practitioner perspective:** As well as discussing the barriers to engagement, the stakeholder interviewees discussed what they considered might work from their varied perspectives. Key among the effective approaches to engagement was seen to be, ensuring researchers and those actually involved in genetics services, are actually part of the communities in which they work, and that they are represented in those services. It was recognised that the diversity profile of clinical genetics and allied services was an organisational issue linked to recruitment policies, and practices, and the need for genetics services to draw from and to reflect a more ethnically diverse recruitment pool. In this context, ad hoc representations to community organisations will have little effect. Rather, effective approaches are seen as ones that are embedded in established, continuing, and mutually beneficial and respectful partnerships with communities. That is, where there are organic links between for example, universities and black and minority ethnic voluntary organisations, and where representation can be observed at both an organisational and community level. The practitioners interviewed in Nottingham underlined the importance of this, highlighting also the need for *'upstream'* discussions engaging communities with the entire genomics agenda, not solely *'downstream'* discussions where engagement is on the basis of a pre-determined agenda. Dr Julian Barwell, Clinical Genetics Lead, University of Leicester and Rose Thompson, Director of BME Cancer Communities who have been working jointly on initiatives that relate to the 100,000 Genomes Project expressed this view in the following terms:

*'I think it is fair about the people being involved and the issues of ethnicity are reflected in our workforce and it comes from having your workforce from your population and ensuring that it is reflected. In our team, we have a number of people who speak multiple languages so we have strong stakeholder community links, we can back it up by going into the community, developing links, looking at triage and so on but you can't do it with any great sincerity unless you can draw on that local population... We are also trying to develop an education outreach post for genomics and we are putting that bid together in the hospital and within the clinical research group and we have some funds we have been using to develop outreach events with BME Cancer Communities' (Dr Julian Barwell, Clinical Genetics Lead, University of Leicester).*

*'The reason that Dr Julian Barwell's team has had success is because they get it. You can live in a very diverse City and you need to comprehend the fact that you need to reach a black and minority ethnic audience and that you have a diverse population, and you need to serve them. If you don't get that you are always going to be asking: "why don't they come to us?'*

*What are the barriers?" You are also not going to equip those who come after you. Community engagement is not about doing one workshop, community engagement is already happening in the community and what organisations need to do is to connect with those experiences' (Rose Thompson, CEO, BMC Cancer Communities).*

4.14 The other approaches that were discussed by stakeholders as having the potential to work were centred on the ability to make links with the 100,000 Genomes Project in a tangible and relevant way. This was by finding a 'story' or a 'hook' on which to develop a research conversation that makes the issue vivid through the 'lived experience'. Therefore, how knowledge is transmitted, received, understood, and also the extent to which it is believed was viewed by stakeholders as a critical consideration, if it is to resonate with communities. As well as the 'lived experience', the extent to which the 100,000 Genomes Project is seen as relevant was also viewed as important from the stakeholder perspective in terms of perceived family risk of cancer and rare diseases. This is because decisions take place in a social context and in that sense a 25% or a 30% risk might matter for those who feel in control of various aspects of their lives. By contrast, in the case of people experiencing forms of disadvantage, there may be many other issues that will take precedence for them. Moreover, practitioners will also make judgement calls about the extent to which a research conversation or the timing of a research conversation is appropriate.

4.15 The notion of information and what is relevant and the need for resources and support was seen as being important to the practitioners themselves in terms of enabling them to develop more of a practical understanding of diversity, and making what organisations do applicable to diverse communities. The following remarks exemplify this view:

*'I think more interactive classroom things and more case scenarios that gives more of an insight more video-based training. I do some teaching and ask about culture and what peoples assumptions are and it is amazing what kind of stereotypes they have in their head and some of my geneticists sit in on my clinics in a different language and they see it, and they say they get an awareness of how hard it is, and I think more exposure. It needs to be part of all GP training, healthcare professionals and not just about cultural awareness but also about the beliefs and their history and how to use interpreters. Most people have no idea of how to work with an interpreter, so it is simple things that would be useful. I don't use interpreters as I speak different languages but when I do it in Polish I see it is very hard, but I think people assume it is easy to work with an interpreter, and natural but it isn't' (Naz Khan, Principal Registered Genetic Counsellor, Manchester Centre for Genetics Medicine).*

*'It is not representative of our country so if we recognise it is not going to be easy to have people in an organisational sense of how we set it up. I would like to do more outreach work and I think we don't outreach enough but that takes quite a bit of resource and it takes having the right connections. I think it is only relevant in so far as that person and the individual and their immediate circle and I think that is culturally more important than lumping everyone under the same category and what they value in terms of health care and what matters to them and when they are thinking about cancer and the fears people have, ethnicity is important but in context' (Debbie Byrne, NIHR Leeds CRF Manager, Deputy Director, Research and Innovation Centre, Leeds Teaching Hospitals NHS Trust).*

4.16 In terms of what works, and in the context of a broad inclusionary approach, a crucial barrier that was explored was how the 100,000 Genomes Project will be aligned in a way that will influence regulatory NICE and commissioning pathways to inform clinical development programmes, and ultimately, clinical practice to the benefit of all patients. There is currently no framework in place for this to happen and in the absence of this, talk about diversity and inclusion can be seen as hollow if ultimately there is no clear pathway for any patient to access effective novel treatments. Eric Low, MBE, Director, Eric Low Consulting and Founder and former Chief Executive of Myeloma UK, is one of the architects of a continuing national Clinical Trial Network of leading experts, hospitals and research centres across the UK. The network runs a portfolio of prioritised clinical trials to accelerate the testing of and access to new myeloma treatments. Eric Low had this to say, drawing on his experience of running clinical trials:

*'I think it is supremely important in the broader sense that there has to be an equality aspect to it and you have to think about it in two ways. Firstly, the way in which a clinical trial is articulated may be biased to certain populations, and secondly, in some disease areas such as cancer, there is no commissioning pathway for the results of academic research to be mainstreamed into clinical practice. So, if you take the national Myeloma XI trial as an example, it was successful, but in some ways, it was not. It showed certain treatments worked better than others, but none of that has translated into clinical practice. So, in the context of the 100,000 Genomes Project, we need to make sure that the funding and the commissioning, and service delivery systems are in place to approve, adopt and diffuse results from the project. Otherwise, if the results just lead to an academic paper presented at an international Congress and not to patient benefit in the NHS, we are not getting the innovation and return on investment promised. The 100,00 Genomes Project therefore needs to somehow influence the pathway, otherwise there is no way for the research results to benefit patients. The whole thing needs to be aligned where findings can influence regulatory health technology and commissioning approval, otherwise patients will not benefit from the research knowledge generated' (Eric Low, MBE, Director, Eric Low Consulting and Founder and former Chief Executive of Myeloma UK).*

#### **b) Focus groups, awareness-raising events and media campaigns**

4.17 The themes arising from the focus groups with black African and black Caribbean participants, the awareness raising events, and the radio campaigns are summarised below, and explored more fully in the ensuing paragraphs:

- a) information and resources produced by Genomics England
- b) Negative historical associations, and fear of sickness, and disease
- c) Safeguarding data and protecting the data of individuals
- d) 100,000 Genomes Project and wider implications
- e) What works from the perspectives of communities

#### **information and resources produced by Genomics England**

4.18 **The information leaflets:** There was a general level of understanding among the majority of participants in the focus groups about DNA, and a general level of understanding that it relates to

cells in the human body. Apart from four stated exceptions, participants said that they had no prior knowledge about the 100,000 Genomes Project. The understanding participants did have about DNA could be described as a veneer of knowledge that had been gleaned from headlines, and this was also true for those who worked in a healthcare setting. The four participants who had previously heard about the 100,000 Genomes Project said they had done so from passing news commentary, and general reading, but their prior understanding did not extend to the actual details of the project.

4.19 At the start of the focus groups, participants were shown two information leaflets about the 100,000 Genomes Project. In addition to the information leaflet, participants were also shown one of two videos from the Genomics England website: *'Introducing Genomics in Healthcare'* and the *'100,000 Genomes Project – An Introduction to Taking Part'*. The responses to the leaflets, with few exceptions, were unfavourable. The comments centred principally on the leaflets being *'uninviting'* and *'uninteresting'* in appearance. They were also seen as too *'technical'*, *'too wordy'* in their use of language, and *'too high level'*. As an illustration, the use of words such as *'gene'* *'genome'* and *'sequencing'* communicated a view to participants that the leaflets were targeted at an audience that was much more informed, and in assuming a prior level of knowledge, whilst this was not the intention, had the effect of bypassing the less informed reader. There were a minority of participants however, mainly from scientific backgrounds, academics, or those with an interest in science or genealogy, who saw the leaflet as imparting useful information on something that they had no prior knowledge of. These views were explained in the following ways:

*'The leaflet is too technical. The question asking: "would you like to help?" should be on the first page' (Focus Group Participant, Sheffield).*

*'In terms of the leaflet, I did not know what a genome was and would imagine that a lot of people do not know. Looking at the leaflet, it is not going to attract me to look at it' (Focus Group Participant, Manchester).*

*'Is this leaflet actually written for the community? Because, this is not really written in laymen's terms as far as I'm concerned so that people could understand. If you were to pick it up, if you were a family member who has got somebody who is part of this project, I've not got a great understanding of it any further than what I have just heard as well' (Focus Group Participant, West Bromwich).*

*'Me, I think it is self-explanatory for me. That looks like a collection of DNA so for me, it's self-explanatory. It does exactly what it says but I have an interest in science and I read a lot' (Focus Group Participant, Bradford).*

*'For me, it looks a bit academic. I could understand it but if you are trying to reach a normal person, genomes and a lot of them its medical terms and if you're not into it, it might mean some highfalutin sounding words. I wonder what the word genomics means in Swahili and to a Masai! If you are thinking of Africans, you should think of something that they could relate to (Focus Group Participant, Nottingham).*

4.20 The leaflets' colours, layout, and visual imagery were described as 'dreary', 'not eye-catching', 'not reflecting diversity', and as such, failing to prompt further interest. The focus group participants suggested that consideration had not been given to broader inclusion, and access needs during the leaflets' conception, development and design stages, with the resulting exclusion of black and minority ethnic communities. This was seen as further undermining the ability to connect with the wider aims of the Project. The following remarks provide an illustration of this:

*'In terms of the project itself trying to reach the BME communities so to speak, that leaflet, there is no representation of BME people in there. If you look at the picture, if you want to reach certain communities then they have to be included. They need to see themselves represented in what you are asking them to participate in' (Focus Group Participant, Ipswich).*

*'If they did have a black person in the marketing leaflets and the video and stuff like that, then maybe we can join dots like I was trying to do, so people could look at it in that way or rare diseases that are currently untreated. But, you can't see yourself in there to kind of ask those sorts of questions, so you felt it's just not for me' (Focus Group Participant, West Bromwich).*

4.21 **The information videos:** The comments made by participants on both the 'Introducing Genomics in Healthcare' video and the '100,000 Genomes Project – An Introduction to Taking Part' were more a little more mixed. The videos were described variously as 'more engaging than the leaflet' and for some, as 'more digestible' in terms of the key messages being communicated, particularly where this had followed a discussion about the genome and the leaflet. For the majority of participants however, the videos were seen as further adding to the confusion about what the Project was asking, and how it related to black people. Moreover, as was the case with the leaflet, a recurring theme was the absence of visual representations of black people in professional and patient roles. These varied responses can be seen in the following remarks:

*'The video is clearer than the leaflet. It tells you what is involved' (Focus Group Participant, Sheffield).*

*'The visual for me is really good because you remember things and it sticks in your mind. It helps you to remember more' (Focus Group Participant, Manchester).*

*'For me not really. There is a lot of information put out about cancer and it is all getting confusing. That film did not explain things to me' (Focus Group Participant, Manchester).*

*'For me, there are some positives but there are still a lot of drawbacks, especially if you are thinking of the target audience. If you are thinking about the ethnic minority, to reach out to everybody, it didn't come across as that. It still came across as middle class, whiteish. People that English is their first language can understand what they are saying. The video and everything, it still sounds more like academic medical' (Focus Group 2 Participant, Nottingham).*

*'My first thought was, where do I as a human being fit into that?' (Focus Group Participant, Ipswich).*

*'If it was to go into the community, they will look at it and say: "well, does that really affect me because all I've seen is Caucasian people. I've not seen any people of my likeness in this video so will that really affect me?" I think they need to be thinking about this. Every time they do a PR material, they need to take into account the diverse community they're going to be addressing with this' (Focus Group Participant, West Bromwich).*

4.22 **Knowledge of Genomics England and the process of obtaining samples:** The issue of legitimacy was also raised by a few participants in the context of a willingness to engage and this related to a lack of knowledge and awareness, not only about the 100,000 Genomes Project, but also knowledge of Genomics England as an organisation. While the majority of participants saw the project as a government or NHS initiative, not everyone had heard of Genomics England, or understood its relationship to the NHS. The leaflets and the video were seen as making the assumption that they did understand as the following remark makes clear:

*'For me the NHS sign is missing. The NHS sign gives it legitimacy. Who is Genomics England? Seeing the NHS sign would encourage me to participate' (Focus Group Participant, Sheffield).*

4.23 The participants that we spoke with informed us that, taken together, the resources and information did not make clear to people what was expected of them. This extended to concerns about what would be involved in the process of participation in terms of time commitments, and how this would fit with the rhythms of working and family life. Also feeding a reluctance to engage were fears about the actual procedure for obtaining DNA samples and this was particularly the case where participants had previously gone through invasive treatments. Therefore, in the absence of information about the process in either the leaflet or the video, some participants were fearful that it might be akin to procedures experienced as part that of their treatment, or on-going treatment, or that it might involve other procedures, or the ingestion of experimental drugs. The concerns about the process and lack of information and knowledge about it were expressed in the following way:

*'Say someone has agreed to take part in this, is it possible that they'd use some of the sample from the biopsy? Those tissues are stored. What I'm asking is, we won't have to go through any more biopsies will we? I've been through two of them and I mean it may be that in the future, my condition gets worse, I may have to go through another one (biopsy) but I don't really want to if I can help it...If I had to donate any more tissues samples, if they were using the ones they had already sorted when I had the biopsy done then possibly' (Focus Group Participant, Nottingham).*

*'This leaflet looks like it is geared towards recruiting people to take part in the project whereas the other was geared towards guiding people to get involved in the project, but it doesn't really say what will be involved in getting this DNA. Do they take my blood? Do they take a sample of my tissue? What are they doing to get this information? So, I am thinking, if I was reading a leaflet and wanted to get involved in this project, I'd like to know what they*

*are going to do to me as part of this research or as part of this data gathering exercise'*  
(Focus Group Participant, West Bromwich).

4.24 The information provided by Genomics England might therefore benefit from making clear, what is required of people, and what participating in the project actually means in terms of the actual procedure of DNA collection for individuals who consent to take part. This would go some way towards avoiding unnecessary speculation and might help to mitigate some of the concerns that people have.

#### **Negative historical associations, and fear of sickness, disease**

4.25 **Contemporary and historical experiences of discrimination and disadvantages:** A recurrent narrative throughout all of the focus groups, among the majority of participants, related to negative associations in the historical cultural memory of black people, in circumstances where they have taken part in clinical research. In relation to the views participants expressed about engaging with the 100,000 Genomes Project, these fears centre on anxieties about the uses to which data obtained will be put, fear of *'experimentation'*, specifically with the bodies of black people, concerns about being used as a *'guinea pig'* and resulting *'ill treatment'*, and concerns about using the bodies of black people to *'manufacture'* diseases, and concerns that money and not treatments is the prime mover, as part of a wider conspiracy. The following remarks explain this:

*'Well, um just um being unsure of what the purpose that they'd actually use the samples for. If it could be done, just like with a simple blood test maybe, right, but I don't think that would be enough...it's just a natural fear when you hear about experiments. It's just a natural fear'*  
(Focus Group Participant, Nottingham).

*'History has taught us so many lessons. Whether they are confirmed or verified, about in the past, certain illnesses developed as a result of experimentation particularly on black people so that was one of my lines of concern'* (Focus Group Participant, Ipswich).

*'Money is driving it. Once they take DNA from people, many treatments will be discovered. People on NHS won't be offered every treatment'* (Focus Group Participant, Manchester).

*'There is a conspiracy out there that they found the cure for cancer years ago and they kept it quiet because they know that if they ever really make this so-called cure for cancer or whatever it is then big Pharma or these companies will go bust. Do you know what I mean they won't gain anything from it and I think as medicine and um research gets even more refined, it just looks like there are more avenues for the big companies to make money as opposed to actually finding a cure or preventing it. You know and as I said, I strongly believe the conspiracy. They already have the answer, and all of this is just gathering information so they can make more money'* (Focus Group Participant, West Bromwich).

4.26 The disquiet about experimentation and ill-treatment, is based on documented historical experiences where black people have engaged with the research community and suffered injury or mistreatment. The two most commonly cited historical examples were the Tuskegee experiment,

and the Henrietta Lacks story.<sup>18</sup> Moreover, while participants did not always have the precise details of what had taken place in those experiments, there was a general level of awareness of the resulting harm and the advantage that had been taken of the bodies of black people in those particular examples. These fears then become conjoined with ideas about participation in clinical research generally, such as the 100,000 Genomes Project, with experiences of wider forms of discrimination at a variety of institutional sites, and what is seen as the potential for historical abuses, albeit separated in time and spatially, to be repeated in contemporary clinical research settings. This includes the design of drugs with the specific purpose of causing harm to black people and taking advantage of their bodies as part of a historical endowment of manipulation and misinformation. The following remarks vividly express these fears:

*'You know they're on about Genome Project and all this but the thing is, at this moment in time, there's people being, I would say, there's people being experimented on today, tomorrow, um, every day of the week and not necessarily in this country, but, the pharmaceutical company in this country are part of that experimentation and it's happening whether we like it or not and in the end, it's like, I'm not saying that we did, but our fore parents in some part somewhere, suffered, and I would say we now are the ones whose starting to show, or it's started happening to us now to where we get certain things but people don't realise the things what's going on in the world. I mean you go for things like malaria, things like that and then they get up to aids and then they get up to other things but at the end of the day, it's once people become more wiser and become more educated then you realise what's going off in the world'* (Focus Group Participant, Nottingham).

*'I was left thinking (after watching the video and reading the leaflet)...they will use this data against us in the future and obviously, programme treatments that is not in our favour. Then there was the other part of me there are two side of the scepticism. They are using us, but I don't know if everyone is aware of this but a long time ago, there was this woman called Henrietta Lacks and she had this super gene thing and they stole her DNA and from there on they've been using it in the research for cancer for ever and a day and her people didn't know about it and it's like they were running out of the cells and they went to her family to see if they could get some more cells and then they (the family) learned they didn't even have the permission to take it in the first place. So, I was thinking to myself are they using this to get more of this information so they don't have to keep going to family members and getting the gene cells and paying loads and load of money? Do you know what I mean?'* (Focus Group Participant, West Bromwich).

4.27 **Genomic medicine, perceived potential for harm, and fear of identifying sickness:** The concerns about the potential for medicines to be developed with the specific purpose of harming black people, was voiced repeatedly by a number of participants in the focus group discussions,

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<sup>18</sup> The notorious Tuskegee Syphilis Study, carried out between 1932 and 1972 by the United States Public Health Service. In that study, poor black sharecroppers in Alabama were recruited to a clinical trial to study the natural progress of syphilis. While the study was in progress, penicillin was discovered to treat syphilis, but the study continued, and the men were not treated with penicillin that could have cured them.

The Henrietta Lacks story, known in the scientific community as HeLa, refers to a poor black tobacco farmer who was diagnosed with cervical cancer, and whose cancer cells were taken without her knowledge and are not one of the key tools in clinical research.

specifically in relation to the 100,000 Genomes project. While it was recognised that the project did have enormous potential to be of wider public benefit, a fear expressed was the potential and/or intent to ‘hurt’ or ‘injure’ black people, and to use black people for ‘token experimentation’. It was also made clear by participants that engagement in the project, at this stage, when the details information and so forth had already been determined without the involvement of black communities, meant that they were possibly not being given the full details about the implications of participating. Moreover, for others, whatever the aims of the 100,000 Genomes Project at this particular moment in time, it was suggested that those aims could conceivably be supplanted down the line, to advance more sinister scientific agendas designed to cause harm to black people. In other words, genomic medicine might be in a position to discover what works in different populations and this would be of immense public benefit. However, pursuing a historical line of reasoning, participants also took the position that the results of genomic studies could be used to find out what is not effective in different populations, to the detriment of black people who absorb a higher level of risk when taking part. Furthermore, for a minority, because these fears were so deep-seated more information and more visually inclusive literature might invite interest but would not be an inducement to take part. The following remarks typify those that were expressed:

*‘When you look in America and they were allowing black men to die of syphilis you know, horrendous, whilst treating the white people, to see how bad the disease could get. You could design medicine that works for a particular race of people and not for a particular race of people’ (Focus Group Participant, Bradford).*

*‘I have my own fears. I mean, I’m quite good at engaging. However, I do feel that I would be more experimented on so I’m not so sure at the end of the day...because the dominant community is the one that has been looked into over time and so now you are a token experiment. So, I could be in danger, not exploited, but exposed in some way. Half the story is revealed, and I am not sure I would trust the whole process’ (Focus Group Participant, Ipswich).*

*‘If the leaflet had a lot more black faces would that entice me to get involved? No. I’d probably listen but it wouldn’t entice me because we’ve see too many where it’s almost the norm to experiment with black people and a lot of things that are happening, it’s almost like they don’t tell us the full story. We are out of the picture and I just think for me its no. No thank you. Don’t touch me with a ten-foot barge pole, even if a black face is up there’ (Focus Group Participant, West Bromwich).*

4.28 The notion of being ‘out of the picture’ and ‘not being given the full details’ is seen as part of a wider pattern of exclusion where agencies fail to fully consult with and engage black communities in the development of policy agendas. In this way, where sufficient time is not allowed, or where engagement is a one-off brief encounter, requests for participation are seen as part of a ‘tick box approach’, not about meaningful engagement, but about the administrative imperatives of government agencies. Two focus group participants expressed this view in the following terms:

*‘The NHS were doing some research, a massive mapping exercise to link directly with a massive budget of how they were gonna spend on tackling disease of delivering clinical care,*

*commissioning. It was the eleventh hour that they were trying to engage with black people because she said that we haven't engaged with any black communities, its only upper class or middle class, I can't remember exactly how she described it, in Harrogate, York and that. I said: "wait a minute, you're now coming here collecting a little bit of information, but it's already gone in?" (Focus Group Participant, Bradford).*

4.29 While there were some participants who were interested in the potential of the 100,000 Genomes Project to identify potential illnesses that might be harmful, a number of participants did not believe this would actually be the case. There were others who talked about their fear of engagement in terms of concerns about looking too closely at their bodies, or their genome revealing something that they would rather not face. This was particularly the case where participants were already dealing with a diagnosis of cancer, a chronic illness, or a potentially terminal one. This was quite separate to the fear of experimentation and was more a case of *'be careful what you look for in case you find it'*, and *'why identify a problem if it has not shown itself'*. There were also the implications of finding something that then impacts wider family relationships and networks as a result of what can be seen as *'bad blood'* in the family. In that sense, the revelation of disease or the potential for disease, through taking part in a genomic study, and what it might open up, the ability to deal personally with what that might be, the necessary support to be able to do so, the wider emotional impact on family members, and potential stigma was an enormous consideration for some participants.

*'For the African community, it is a very big issue. If you go and find out some hereditary disease in your family, they even warn you, "that family, don't even try to get even close to them". My daughter has a friend, the mother has cancer and yesterday my other girl said, "does it mean that if you end up with this person your child will have cancer"? You know? She is already considering that, and you know, some people can hide that because even with sickle cell, I know so many marriages that didn't go ahead because they were AS. In Nigeria, the churches will advise you. If you are both AS they won't certify the marriage' (Focus Group Participant, Nottingham).*

*'I hope I'm not generalising, but I have a feeling about how people respond to a diagnosis, like for example, if I did this genome and I've got my kids, how am I going to feel about telling my kids that there is something that is going to affect them through me because, whereas I might have the resilience to say: "OK", it might freak one of my kids out. You understand? I mean you guys have been diagnosed. When I had my diagnosis maybe I'm a blasé sort of person but it's there, but other people might be crying' (Focus Group Participant, Nottingham).*

*'I have enough on my plate never mind trying to find out what else could be wrong' (Focus Group Participant, Manchester).*

### **Safeguarding data and protecting the data of individuals**

4.30 **Privacy, trust and confidentiality:** There were a minority of participants who had absolutely no concerns at all about participating in the 100,000 Genomes Project, seeing it as akin to donating

blood, and as important in terms of the potential for wider public benefit, providing they were given assurances of confidentiality:

*'I have no concerns as long as it remains confidential' (Focus Group Participant, Sheffield).*

*'For me if it could help anybody, I am more than willing to do it' (Focus Group Participant, Sheffield).*

*'This to me would be like the Anthony Nolan Trust where you give your blood and they screen it and they have your details and if anybody needs bone marrow, they have your information on a database, so they can access that. That's what this reminds me of, so they can recall it anytime because they've got everything' (Focus Group Participant, West Bromwich).*

4.31 The majority of participants however had fears about the genome becoming an important element in relations between pharmaceutical companies, institutions, commercial interests and individuals, and this affected how they viewed taking part in clinical research and the 100,000 Genomes Project. These fears were to do with questions concerning; how their data would be stored and safeguarded; whether it would be secure; who would have access to it, and anxieties about the potential for their lives and the lives of their families to be adversely impacted if their data *'got into the wrong hands'*. There were also worries expressed about the genomic data of individuals being used outside what consent had been given for, and fears about genomic data being *'manipulated using technology'*. Indeed, these were voiced as concerns even in those circumstances where individuals were favourably disposed to the 100,000 Genomes Project, indicating that an individual can hold contrary positions about scientific research, at the same time. There were also questions raised about systems for redress as it was seen as inevitable that things would *'go wrong'* at some stage. Indeed, whilst participants were advised that Genomics England provided assurances that data would be stored in a safe, secure and anonymous way, this explanation was not necessarily trusted or believed. There were a number of participants who took the view that, in an age where systems are linked, and data computerised, 100 per cent guarantees of safety are meaningless. There were a number of participants who also expressed worries that the database might be linked to unethical comparative experiments over time, involving black people with cancer and rare diseases, as well as links to the Windrush saga, and nervousness about possible links to the criminalisation of black people via links to the Police DNA database. The following remarks are illustrative of these views:

*'For me, if you are going to be collecting this data, what happens to it? What is it going to be used for? Who is going to have the data and how does that affect us as black people? I'm just laying it on the table' (Focus Group Participant, Bradford).*

*'The basic idea I love. However, it is what they do with the information after. The idea is perfect. I have my grandchildren and if I knew there is something preventative that would give them a great life, then I would get involved. My greatest concern is what will they do with my DNA sample and what is going to happen with that' (Focus Group Participant, Manchester).*

*'If it was me an an NHS patient, I would be concerned about my privacy and if I was to take part in the blood sample, where do you take my blood and what do you use it for and will I get those results as accurate as you say' (Focus Group, 2 Participant, Nottingham).*

*'Is there a scientist somewhere that is going to develop a drug that attacks the genes of black people to eventually kill us off? I mean, you know we have been experimented on and had similar sort of literature research and in the end, it was just a way to look at Syphilis over a long time and black people weren't treated. So, I'm not so sure about the motives behind this. Also, knowing black people are more likely to be on the DNA register that the Police gather, so there's lots of alarm bells ringing for me about how this data is going to be used, and can government be trusted with your data' (Focus Group Participant, West Bromwich).*

4.32 **Genomic data and third parties, fears about future privacy:** The reassurances of privacy and confidentiality some participants argued, might not necessarily hold true in perpetuity if there was a shift in official thinking, and that whatever the good intentions of decision makers today, regulations mandating protection could change. Moreover, it was felt that regulations and rules to prevent the misuse of data cannot foresee every eventuality. There was therefore seen to be a need for complete transparency and honesty around what confidentiality actually means in practice, and its potential shortcomings. Whilst there is a high level of trust in the NHS, there is a level of mistrust where access to genomic data involves the NHS working with pharmaceutical companies in a commercial relationship, and in the context of a healthcare system that is seen to be in crisis and looking for opportunities to increase its resources. There was also a concern that the 100,000 Genomes Project was focused on treatment rather than prevention, as well as concerns that diseases disproportionately impacting black people, do not receive their due attention.

*'My particular concern is that I do not have a great deal of trust in pharmaceutical companies. When they can produce drugs for black people, they don't do it. I am concerned that the data will be passed on free of charge. What are the ethics around this? I have trust with the NHS however, I have to think; how is the data going to be used by them? Would it be sold? Who will benefit from this? The idea is good, but it seems like healthcare is in crisis. The whole idea of personalised medicine is expensive so where are the resources going to come from (Focus Group Participant, Sheffield).*

*'I would be concerned about like, where your DNA's going. I mean, not trying to theorise about, I don't know, those conspiracy theories and things like the pharmaceutical companies uses your DNA to make money but I think that is a concern for the community and thinking like say, further ahead into the project which is to improve care and stuff, but it is not necessarily the care but about what you are doing before to prevent these types of illnesses. Like I know it's possible this can be down to lifestyle factors and things like that. That is an important factor for people. It's not necessarily about the care' (Focus Group 2 Participant, Nottingham).*

4.33 The other third-party organisation that participants expressed concerns about were insurance companies, and the possibility of them accessing genetic information about individuals. The line of reasoning went, if genetic data can be used to potentially identify and predict certain

diseases, and inform treatments, they could also potentially be used to deny travel, life and other forms of insurance to individuals deemed 'at risk' and was therefore seen to have direct social and practical consequences. Furthermore, whatever the official line, participants were concerned about whether they should disclose taking a genomic test to insurance companies, as they were concerned that there would be penalties for failing to do so at some point, if the test 'revealed something'. Two of the participants put it this way:

*'I heard about the genomes project four years ago in the media and the biggest fear was insurance companies and if they got hold of that information, people would find they could not get insured and if they knew you have a history of cancer, history of this, history of that they said how secure is that information? They said insurance companies like car companies, they all share information. Who is gatekeeping that information? That's why the black community is saying, "you're not getting my confidential information"'. (Focus Group Participant, Bradford).*

*'The question is, because people know that you are susceptible to certain disease, how does it affect you? Is it something you should disclose? They tell you that in the film you don't have to disclose but it is a reality because the insurance company will say, "You knew but you did not disclose it to us" and most people will be thinking, "I don't want to get involved in that". Also, because some people in the BME communities, they will create issues about your family'. Whether it is covered or not, you are telling a lie' (Focus Group Participant, Nottingham).*

### **The 100,000 Genomes Project and wider implications**

4.34 **Fears about being left behind:** As already explained, individuals can and do simultaneously hold contrary positions about scientific research, that is, being interested and keen to engage, and at the same time, not wanting to engage because of fears about the wider implications of taking part, and a lack of trust in the purpose and the process of clinical research, referred to as a 'Jekyll and Hyde' situation. This again became apparent when exploring participants' views about what they saw as the implications of not being represented in genomic studies. The fear of participation was for some, linked with concerns that non-participation would mean knowledge about diseases that disproportionately impact black people would be limited, as would the development of innovative therapies, and knowledge about the efficacy of therapies in different populations. At the same time, there was concern that it was about trusting those who are doing the engaging and who have built up trusting relationships in the community:

*'If they are using the data to develop diagnoses and we are not in it then we are going to get misdiagnosed. I see in the video of the Asian boy with diabetes, they give him tablets instead yeah. Obviously, they are making that decision based on this thing yeah, and like, if our DNA is not in it, would we be on the wrong medication because we can't match...one of my concerns is it's not gonna match me when they start using this technology' (Focus Group Participant, West Bromwich).*

*'It is a good opportunity for them to find out what is in my genes, which could also help my family' (Focus Group Participant, Manchester).*

*'While some people might say it would help other people, I think our communities would say they don't care because the bottom line is that if they get exploited just because they want to support the future generations, we die of this, our children are going to die of this so it doesn't matter so people will sit back and say they don't care...Every time you sit round a table, the powers that be say they want certain people, they want certain communities and if you go to Kenya and talk about MMR, the one here that became a big issue, back home if you are offered those injection (MMR), people won't take it, but if you are offered those injections in the local community, people will accept it and I think those clinics, HIV clinics in Kenya, when they set them up, people would say, the Mzungu's (meaning white people) are coming. They want our blood. But, when you get local people it is different. They will come' (Focus Group Participant, Nottingham).*

4.35 There was also a concern that as genomic medicine is the way of the future, its development will proceed regardless of whether black people choose to engage, and that if they fail to engage, they will be left behind. The importance of inclusion in the 100,000 Genomes Project was also seen in the context of the wider benefits it could potentially confer on the future welfare and well-being of family members such as children and grandchildren, as well as advancing medical knowledge which might not benefit individuals in the here and now but could potentially benefit future generations and humanity as a whole. The concerns of family were seen as something that would influence a decision to participate. Moreover, not wanting to engage was not necessarily a fixed and unchanging position, but could be a conflicted one, depending on circumstances and context. The following remarks illustrate these varied views, as well as conflicted notions of participation and wider public benefit:

*'It's the bigger picture that they say on there, if, like I said, I've got a son, he hasn't got any children yet, but he may have a son as well. So, if in the future, um, taking part in something like that advances the drugs or the medicine, that helps, then for the benefit of the future generation' (Focus Group Participant, Nottingham).*

*'Both my parents had cancer, so I think my views have changed. That's why I would do what I could for my community to have their information mapped' (Focus Group Participant, Sheffield).*

*'It is important to take part, as looking ahead in years to come when advancements are made with personalised medicine, then if the Black community were not there in the first place, then how will they know to treat future generations? They need the information first. This can lead to more health inequalities. More of the same' (Focus Group Participant, Manchester).*

*'I see this as a selfless exercise where you take part, knowing you will never ever benefit but it's for the wider picture like generations to come, your children, that type of thing. That's the way I see it. So, if someone was to take part, you wouldn't expect to get the results*

*straight away, that's the first thing. But for me, it's an outright no really because I just don't trust the process at the moment but I'm trying to stay objective for this whole thing. I was trying to put myself in the position of somebody who might have a rare disease or might have a family with rare disease like sickle cell. I've got a rare skin disease myself as well and you know, if you were in that type of situation, you would want to know how you could stop, treat, whatever that condition for your future family, your kids, your grandchildren and stuff like that. So, when I speak about things like sickle cell. I've seen kids die from it. I was thinking would this be a useful exercise like this situation and that's me trying to be objective, but my gut feeling is to stay away from it' (Focus Group Participant, Ipswich).*

*'They said you can give your information and they'll do the research, but it's for generations down the line, maybe you're benefitting generations down the line, not necessarily you as an individual so it is just gathering, as somebody said before, gathering a lot of your information. With genomes, certainly they can manipulate them, they'll do whatever they want with them, and it's almost going for private companies, companies for profit, that's what jumped out for me the NHS and companies for profit will be doing some sort of deal in the future. That's what came out for me. It made me jump as well' (Focus Group Participant, West Bromwich).*

#### **What works from the perspectives of communities:**

4.36 **Marketing, promotion, visual representation, and understanding diversity within black communities:** A central issue raised by participants concerning how to connect with diverse audiences, was the need for messages to be more nuanced and targeted in how they are conceived, as well as how they are transmitted. Whilst the term *'black community'* is used to denote a group of people sharing a particular historical and contemporary experience, it is seen as an over-simplification in practical terms as the black community does not represent a single unvarying set of interests and concerns but is diverse in innumerable ways, not least, gender, age, education, nationality, and so forth. This is in much the same way as the term *'population'* when referring to the UK for example, does not imply that everyone is the same:

*'It's basic marketing isn't it? So, you actually ask the question and have some reference, you would say something like what affects so many people and so many families, you know. If there was a question on there, you would be more likely to pick it up. Like do you suffer from X. In this room we've got 9 women and 5 men, and we are all different and what appeals to us is different and so that is the challenge that this has' (Focus Group Participant, Bradford).*

4.37 The need for visual representation and recognising the diversity of black people, linking information about the 100,000 Genomes Project to life experiences is also seen as important to making a meaningful connection, and to imparting a degree of confidence that any potential benefits from clinical research are for everyone. While the focus for this commission was on black African and black Caribbean groups, the point was raised throughout the research that other minority ethnic groups, and other socially disadvantaged groups have been similarly excluded from discussions to inform policy, particularly speakers of principal languages other than English, or those that are not comfortable with what, for many agencies are seen as the most obvious tools of self-

expression such as questionnaires, meetings, forums and so forth. It was therefore seen as important to have clear and concise information, visually appealing, in other languages, also recognising that not everyone is literate in their own language or is able to see and hear. Information therefore needs to be made available in a range of forms through trusted sources such as a GP, through community advocates, and venues such as hospitals, churches, and community centres, through social media such as Instagram, Facebook, targeted TV campaigns, in large prints, and areas frequented by black people.

4.38 In terms of making links with real life experiences, many of the participants in the focus groups and the events stated that case studies featuring people who has been through the process would help in forming a connection and taking notice as the human focus makes one sit up and look. In terms of the human focus it was suggested that less of an emphasis on the science, and more on what it means for people would make the project seem more relevant. The representation of black communities was seen as important, as was appealing to different audiences within black communities. Amdani Juma, Director of the African Institute for Social Development explained why it was important for messages to be nuanced and take account of differences in a way to foster a real connection:

*'The African communities are younger in terms of the population and we tend to use technology, mobile phone technology. Recently we did a large study with Nottingham University on a project to get Africans to test for conditions and in particular to get them to test for HIV, and that project, using mobile phones and sending them regular texts with a proverb about health wealth and wisdom was a big success. We got a 70% response and we were only expecting 20%. There is a lack of information and centres for accessing African centred information....African people don't want to come and they are very unlikely to discuss it with their family and people may see it from a spiritual angle so people don't come forward. So, if we can educate more people, help them to engage more and we can get personalised treatment that is great. So, we are supportive. It might not benefit you now, but it might benefit someone from your lineage' (Nottingham Radio Show Kemet 97.5FM, Amdani Juma, African Institute for Social Development).*

4.39 The participants attending the focus groups and events made it clear that they would be keen to engage in more in depth discussions to have access to more information. What is clear is that, in common with the population generally, no one approach will suit everyone. Rather, it is about interrogating existing ways of doing things and modifying existing approaches where it can potentially broaden engagement and seeing the diversity in black communities and applying different communication and engagement styles. The patient organisations that have supported this research have a tried and tested record of working with and supporting patients and carers nationally, and running successful information and awareness raising engagement health related events, in partnership with statutory, voluntary, and other health agencies including NHS Trusts. They are therefore important organisations for agencies to develop meaningful relationships and partnership with.

4.40 **Investment in diversity:** There was correspondence with the views expressed by practitioners and the focus groups, events and radio campaigns that an effective way of engaging is

having people on the ground who are experienced in community outreach, or who are based in third sector organisations, and/or who are from the community. It was however made clear that anyone could be a trusted member of the community. This is because trust is seen as being gained by investing time in the development of relationships in the community by people with a shared value set and experience. A positive step forward was also seen as meaningful strategic investment in equality at decision-making levels, not tokenistic representation where diversity may be enhanced as a visible level, but little changes and it remains *'business as usual'*:

*'I was a non-exec director in the NHS and I was sitting with consultants and others twice a month, having to wade through strategic development of this area for the NHS commissioning, and I'd done an MBA but I'm talking about reams and reams. I got to one stage and I thought: "I'm getting paid good money for doing nothing". I just felt the lack of parity and I said to them, I'm going to have to resign...some of the faces that you see picked to go on the Boards they are not people that will challenge stuff. Some of them, you don't even hear them speak or contribute in the meeting....They are tactical allies, it's a tick box. They need to present a glossy pamphlet and to tick those boxes' (Bradford).*

4.41 **Moving from theory to practice:** A key component in moving from the rhetorical level to action is not only acknowledging that there is a need to make general patient information about events and the design and the promotion of them both relevant and inclusive in cultural and visual content, in tone and in style, but to take action on this and different approaches to engagement. Among the successful approaches employed by patient organisations are: community health events at national and local venues; deliberative and participative spaces that engage communities in a discussion about a range of health issues and treatments; information dissemination and interaction through community radio stations, targeted shows on mainstream radio, and via social media, and engagement through existing community forums and educators. These were some of the methods adopted in this engagement project which, it was suggested that the should be part of a continuing and sustained campaign:

## **5. Conclusion, synthesis and recommendations**

4.42 This qualitative research and community engagement project has explored widening participation from the perspectives of key stakeholders and black African and black Caribbean communities in England as, while there is no problem with recruitment of black and minority ethnic people to the rare diseases component of the 100,000 Genomes Project, the figures for cancer do reveal under representation, particularly in relation to black people of Caribbean origin. The key findings are that there is correspondence between the views of stakeholders on barriers to participation, and the black communities who participated in this exercise. These barriers centre on historically grounded fears about engaging in scientific research, and fears about the motives of the scientific research community. The way information is developed, the means through which it is transmitted, and the extent to which it is believed was also seen as a fundamental barrier.

4.43 As well as barriers on the community side, there were also institutional and individual impediments that were identified from a service planning and delivery perspective. These relate to; unquestioned assumptions about the way things are done; a lack of investment of time in

community engagement; adopting a tick-box approach to engagement and failing to see that there is an equality vacuum where decision making becomes culturally bound due to a lack of diversity in organisations. In addition, some community participants expressed concerns about the extent to which benefits from any construction of knowledge would actually accrue to black patients. In a similar vein, an important question was raised about benefits for patients as a group, and the need for a clear articulation of the way in which the results from the 100,000 Genomes Project will actually feed into and inform frontline clinical programmes and practice.

4.44 The fears articulated by community participants about engaging with the scientific research community sits hand in glove with individuals who simultaneously hold polar opposite positions, vis-a-vis, a fear of engaging, whilst also seeing potential benefits for their families and future generations. There are also concerns among both the stakeholders and the communities that participated, about what a continued lack of representation in the 100,000 Genomes means in the future, for those communities not represented on the genomic database. There were therefore calls to extend the timescale to allow for the sustained engagement work to address some of the barriers identified.

4.45 The following recommendations, which are grounded in the key findings are as follows:

### **Recommendations**

1. Genomics England make the report available to organisations with key influence in clinical research and commissioning such as the National Institute for Health and Care Excellence (NICE), the Wellcome Trust, Public Health England, the Medical Research Council, Cancer Research UK, Genetic Alliance UK, Rare Disease UK, National Voices, the National Cancer Research Institute, and those involved in clinical research into cancers and rare diseases.
2. Genomics England seek to engage Public Health England, the Medical Research Council, the Wellcome Trust, Cancer Research UK, Genetic Alliance UK, Rare Disease UK, the National Cancer Research Institute, other stakeholders, and equality and diversity specialists, to lead the development of an equality impact assessment protocol, within the statutory framework set by the Equality Act, 2010. This should include appropriate guidance for assessments to be undertaken as a mandatory requirement in the conception, development and carrying out of sponsored clinical research, to ensure diverse representation and the more even distribution of its potential benefits.
3. While this project has focused on black African and black Caribbean communities, as part of a process of wider engagement, Genomics England should look to extending recruitment to the 100,000 Genomes Project beyond the current October deadline. It should continue to proactively engage black and minority ethnic communities more widely. Within the statutory framework set by the Equality Act 2010, this should form part of a coherent and on-going programme centred on the development of equality audited relevant and accessible information about the 100,000 Genomes Project, what participation involves, as well as awareness raising, and targeted events, developed with the black and minority ethnic voluntary and community sector, rather than one-off brief encounters

4. Genomics England seek to ensure that the data and findings from the 100,000 Genomes Project are used to influence regulatory NICE and commissioning pathways to actually inform clinical development programmes and ultimately, clinical practice. This is to ensure that patients will actually benefit from the research knowledge generated, and that the wider aspirations of the 100,000 Genomes Project for patients with cancers and rare diseases are fully realised.
5. Alongside the collection of clinical data, the contribution of those participating in the 100,000 Genomes Project should be captured qualitatively. This should form an integral part of the process of reporting on outcomes from the 100,000 Genomes Project focusing on participants' experience from a social, emotional and practical perspective, alongside their individual reflections, in order to bring symmetry, balance and visibility to their experiences, alongside clinical findings, as part of an inclusive exchange to inform clinical research, policy and practice.
6. That the report be circulated to the High Commissioners of African and the Caribbean countries in the UK.

## Appendix A – Focus Groups

### Focus Groups Participants

Focus Groups							
Number Participants	Male	Female	Age Range	Disability Yes	Disability No	Caribbean	African
<b>Nottingham Focus Groups x 2</b>							
9	9	0	50-65+	2	7	9	0
6	1	5	30-44	0	6	1	5
<b>Sheffield Focus Group</b>							
7	3	4	50-65+	1	6	7	0
<b>Manchester Focus Groups x 2</b>							
6	6	0	35-65+	0	6	6	0
9	1	8	40-64	4	4	0	9
<b>Bradford Focus Group</b>							
9	5	4	25-65+	3	6	9	0
<b>Ipswich Focus Group</b>							
9 <sup>19</sup>	3	6	40-65+	1	6 <sup>20</sup>	5	2

<sup>19</sup> Two people from White Other communities who identify with African and African Caribbean communities also participated

<sup>20</sup> This does not include two participants who elected not to say

## Appendix B – Awareness Raising Events and Radio Campaigns

### Sheffield Awareness Raising Event

Presenters	
Vivienne Parry, OBE	Head of Engagement, Genomics England
Rose Thompson	Director, BME Cancer Communities
Julie Atkey	Co-operational Lead and Genomics Education and Training Manager, Yorkshire and Humber, Genomic Medicine Centre, St James's University Hospital
Sophia Skyers	CIBS IQ Research

### Manchester Awareness Raising Event

Presenters	
Vivienne Parry, OBE	Head of Engagement, Genomics England
Rose Thompson	Chief Executive BME Cancer Communities
Professor Gareth Evans	Professor of Medical Genetics and Cancer Epidemiology, Manchester Centre for Genomic Medicine
Marcella Turner	Can-Survive UK

### Kemet 97.5 FM – Nottingham Radio

Christine Belle Radio Presenter - Mid Morning Show	
Panel Members	
Rose Thompson	Chief Executive, BME Cancer Communities
Amdani Juma	African Institute for Social Development
Rupert Aikman	Director/Nutritionist, Healthy Eating Solution
Bishop Gary Howe	Advanced prostate cancer, late diagnosis and misdiagnosis, family history
Julian Barwell	Leicester Clinical Genetics Lead, University of Leicester
Cherry Harrison	Longterm diabetic patient
Sandra Sibblies	Advanced breast cancer linked to family history

### Legacy FM – Manchester Radio

Natalie Teniola Radio Presenter	
Panel Members	
Vivienne Parry, OBE	Head of Engagement, Genomics England
Rose Thompson	Chief Executive, BME Cancer Communities
Marcella Turner	CEO, Can-Survive UK

## Appendix B – Stakeholder Interviews

Stakeholder Interviews	
Vivienne Parry, OBE	Head of Engagement, Genomics England
Dr Catherine Byrne	Consultant Nephrologist, Nottingham University Hospitals NHS Trust
Professor Gareth Evans	Professor in Medical Genetics and Cancer Epidemiology, St Mary's Hospital, NHS Foundation Trust, Manchester Centre for Genetics Medicine
Julie Atkey	Co-operational Lead and Genomics Education and Training Manager, Yorkshire and Humber, Genomic Medicine Centre, St James's University Hospital
Debbie Beirne	NIHR Leeds CRF Manager - Deputy Director, Research and Innovation Centre, Leeds Teaching Hospitals NHS Trust
Eric Low, MBE	Founder and Former Chief Executive, Myeloma UK and Director, Eric Low Consulting
Dr Simon Ridley	Director of Research, Myeloma UK
Rosemarie Finley	Chief Executive, Myeloma UK
Naz Khan	Principal Registered Genetic Counsellor, Manchester Centre for Genetics Medicine
Dr Julian Barwell	Leicester Clinical Genetics Lead, University of Leicester
Marcella Turner	Founder and Chief Operating Officer, Can-Survive
Rose Thompson (Hon. Doc. Soc. Sci)	Director, BME Cancer Communities
Professor Frank Chinegwundoh, MBE	Consultant Urologist, Barts Health NHS Trust
Clem Turner	Chairman, Caribbean and African Community Health Project Support Forum Ipswich
Felicia Robinson	Secretary, Caribbean and African Community Health Project Support Forum Ipswich
Linford Sweeney	Black History Educator, Genealogist, Coach, Mentor, Poet, Author
Grace Salmon	Secretary, Bexley African Caribbean Community Association
Dr Freyja Docherty	GMC Genetic Counsellor, Sheffield Teaching Hospitals
Rupert Aikman	Director/Nutritionist, Healthy Eating Solution

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