SEthical, legal and social issues in Diversifying Data: Literature review and synthesis

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Summary

Advances in technology have resulted in the ability to sequence entire human genomes as a routine, relatively inexpensive, investigation in healthcare. This offers many promises of personalising, stratifying, and targeting healthcare with an understanding of genetic susceptibility to particular diseases or conditions. However, research collections (databases, biobanks etc) that underpin these developments are significantly skewed towards populations of European ancestry meaning that our understanding of genetic susceptibility (or indeed of genetic protection to disease) is less good for many other populations in the world. Just as a dermatology text book skewed towards skin problems on white skin may be less useful to black populations, so genomic knowledge derived from one particular ancestry means it may be less useful to people with different ancestries.

The need to diversify genomic data, to improve the evidence base for genomic medicine for all ancestries, is well recognised, but is more complex than simply increasing the collection of data from people from a range of ancestries. We reviewed the literature to understand the challenges of diversifying genomic data to identify key ethical, legal and social issues. Our findings were:

1. Many research practices are exclusionary and need to change. Examples include approaches to recruitment or data collection that do not consider the cultural setting in which potential participants are situated. Research also often lacks reflexivity about diversity on the part of researchers and research institutions.
2. Co-design is key to identifying and avoiding potential problems around data diversification. This requires an understanding of the concerns of underserved individuals and communities regarding exploitation and stigmatisation, as well as issues of data ownership and sovereignty. Without attention to group as well as individual concerns, participant engagement may become tokenistic which in turn risks exacerbating existing, as well as creating new, inequalities.
3. There are wider structural issues that influence researchers' and participants' attempts to generate diverse data. For example, (a) some researchers view data as neutral, but this ignores the social construction of data and technologies, and their tendencies to reflect societal inequalities. (b). Efforts to diversify data should be contextualised within the historical trajectory of structural racism and legacies of colonialism. (c) Classification and categorisation of populations have political consequences and need to be closely interrogated.

These findings show that deliberation between researchers and participants, during all stages of research from planning and recruitment through to analysis, interpretation and dissemination is key to successful diversification.

The review concludes that we must move beyond the recruitment of individuals from underserved groups as the endpoint. Diverse data, are not ethical in and of themselves. If the wider social, historical, legal and political contexts that shape the lives of potential participants are neglected, existing issues are likely to be exacerbated. Ethics must be positioned at the forefront of biomedical research, but also throughout it – and must be seen as more than gaining research or institutional review board approval. Co-design should be at the heart of this. Participants need to be regarded as active researchers and knowledge makers, with participant engagement at the conception of research and actively threaded throughout. Moreover, addressing inequities requires shifting the focus from diversifying data towards enabling diverse ways of knowledge making. This can only be achieved via institutional change and cultivating a research and enterprise culture that incentivises diversity through all aspects of the research process. We conclude that data diversification requires consideration of the broader socio-political context within which genomic developments are taking place, and a focus on co-producing a genomic enterprise with diverse participants as active researchers and knowledge producers.

Many individuals have contributed to the design, and analysis of this research. For the full list of contributors and co-authors please see Appendix D).

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1. Introduction

The role of human genomic variation in global health and disease is understood only to the extent that we can collect, process, and compare DNA data from large, diverse populations. To date, the majority of DNA data collections consist of genomes from people with mostly European ancestry (Aicardi et al. 2016; Mills and Rahal 2020; Sirugo, Williams, and Tishkoff 2019; Popejoy and Fullerton 2016). This lack of global representation in genomic databases persists despite increasing awareness and collaborative international efforts to improve representation (Nature Editorial 2019; H3Africa Consortium et al. 2014; TOPMed[3]; PAGE[4]). The aim of this review was to provide a comprehensive overview of literature on the ethical, legal, and social implications of increasing diversity in genomics research and to offer suggestions or recommendations for future practice. A multi-disciplinary team of experts in the field was assembled to review our preliminary findings, and this report includes their reflections.

1.1 The importance of comparison in interpreting genomic variation

All humans have approximately 99. 9% of DNA sequence in common. Exploring the 0.1% that varies amongst us can advance our understanding of how genetics contributes to disease. This 0.1% constitutes in the region of 5 million genomic variants per person. Some genomic variants may be rare in particular populations but more common in others - and knowing whether a variant is truly rare across the global population, or rare only in particular populations, may be helpful in deciding whether it is important in disease aetiology (Auton et al. 2015). Variants that are common in a population are unlikely to play a major role in a disease causation, although the combination of many common variants may provide insights into the heritable component of common diseases. Whether or not a genetic variant will result in disease often depends on a multitude of other factors including genetic as well as environmental, random or unknown factors.

A person's genomic sequence is identified by aligning DNA readouts from an individual to a 'reference' genome. Which variants are identified will depend to some extent on the composition of that reference genome.[5] The identified variants are then interpreted through

[3] Trans-Omics for Precision Medicine (TOPMed) Program https://www.nhlbi.nih.gov/science/trans-omics-precision-medicine-topmed-program

[4] Population Architecture using Genomics and Epidemiology (PAGE) Consortium https://www.genome.gov/Funded-Programs-Projects/Population-Architecture-Using-Genomics-and-Epidemiology

[5] A reference genome is assembled from a number of individual donors, for example, the most recent human reference genome GRCh38, is derived from >50 genomic clone libraries (https://www.ncbi.nlm.nih.gov/grc/help/faq/). Given that the reference genome represents a limited number of people, some variations regarded as 'reference' will in fact be linked with disease (Chen and Butte 2011). During

comparisons with large genomic datasets to assess their relationship with particular diseases or conditions and to see whether they occur frequently in general (rather than disease specific) populations.

The ability to interpret the significance of genomic variation, both for individual patients, and in terms of their contribution to disease in populations, is therefore contingent on the availability of relevant data for comparison. Prior to the advent of whole genome sequencing, Genome Wide Association Studies (GWAS) were often used to determine whether variants throughout the genome are associated with disease. To date, the vast majority of GWAS, and indeed genomic studies in general, have been conducted on data from participants of European ancestry (Martin et al. 2019; Mills and Rahal 2020) while this ancestral group forms less than 16% of the global population (Nature Editorial 2019). Variants associated with a particular disease in people with different ancestral backgrounds are therefore less likely to be detected so that insights from studies focussed on European ancestry groups may not be as relevant to other populations. In what follows, we discuss the potential clinical, ethical and societal implications of this lack of diversity in many genomic studies performed to date.

1.2 The consequences of a lack of diversity in genomic datasets

Deleterious clinical consequences of underrepresentation in genomic datasets are well-documented. For instance, there is a higher chance of benign genomic variation (i.e., genomic variation that does not have a health effect) being interpreted as disease-causing. This is because very low frequency of a variant in population databases may be used as 'moderate' evidence to support pathogenicity – it is assumed to be rare because the variant prevents people becoming healthy adults (Richards et al. 2015). A study by Manrai et al. (2016) analysed five genomic variants initially thought to predispose to hypertrophic cardiomyopathy, partly on account of their supposed rarity. The authors established that the variants were in fact quite common in some ancestral groups (seen in more than 1 in a 100 people), and reclassified them as benign. On reviewing their records, they found that patients affected by this misclassification were of African or unspecified ancestry. This meant that unnecessary screening or surveillance may have been recommended in individuals, and their relatives, or necessary screening may have been withdrawn because it was thought they had tested negative for the genetic variant causing heart disease in their family (when in fact the variant tested was not the cause of this disease). This might have been avoided had people with similar ancestral backgrounds been adequately represented in the population databases against which these variants were

genomic analysis, short fragments of a person's DNA sequence are aligned with the reference sequence, and fragments that cannot be aligned to this reference are discarded. Some sections of the genome can be harder to align than others(Wang et al. 2022), which may in part be explained by variation in some genomes not aligning to a reference genome that represents a particular ancestral group. The Human PanGenome Project is an initiative to attempt to create a more diverse reference genome with a graph-based, telomere-to-telomere representation of global genomic diversity (Wang et al. 2022).

compared. Whilst such stark examples are probably less likely in genomic practice today, it remains true that genetic variants found in some ancestral groups are more likely to be interpreted as 'variants of unknown significance (VUS)' because insufficient evidence is available to label them as pathogenic or benign. For example, Kurian et al. (2018) used a diagnostic gene panel in patients with breast cancer and found that it was more difficult to classify variants effectively in populations that were not of European descent. This under-representation of non-Europeans resulted in a higher proportion of variants being classified as VUS. (Petrovski and Goldstein 2016; Caswell-Jin et al. 2018; Kurian et al. 2018).

Concerns have also arisen about how underrepresentation in genomic datasets might exacerbate existing, or create new forms of inequalities (Need A.C. and Goldstein D.B. 2009; Bustamante, Burchard, and De la Vega 2011; Petrovski and Goldstein 2016). Many envisage that multiple variants across the genome ('polygenic scores') will soon be used to stratify population screening approaches[6] yet the lack of diversity in GWAS data will mean that such stratification is less effective- or the scores will be inaccurate- for people with non-European ancestry (C. M. Lewis and Vassos 2020).

Lack of diversity in genomics can also affect societies more generally. For example, since science and technology developments reflect our priorities and values, overrepresentation of data from people of European ancestry could send a message that this group is somehow more valued, in turn exacerbating extant global inequalities and social divisions.

1.3 Calls for diversity

Recognition of the bias in genomic datasets have resulted in calls for improvements in diversity[7] (Green, Guyer, and National Human Genome Research Institute 2011; Hindorff, Bonham, and Ohno-Machado 2018; Hindorff L.A. et al. 2018; Fatumo et al. 2022; Popejoy et al. 2018). However, historical biases may be difficult to remove given that these datasets often have many years of follow up providing unparalleled longitudinal data that is difficult for new, more diverse cohorts to catch up with. A growing body of literature also points to difficulties with achieving diversity because of underlying social, political and historical contexts (George, Duran, and Norris 2014; Reardon 2017; Ilkilic and Paul 2009). Moreover, a key consideration in diversifying data is that the way in which diversity is imagined and conceptualised can affect the

[6] 'Genome UK: the future of healthcare' government report (https://www.gov.uk/government/publications/genome-uk-the-future-of-healthcare/genome-uk-the-future-of-healthcare). Our Future Health – 5 million participants.*Our Future Health can help researchers explore important questions about the potential uses of new genetic risk scores in health care*'. (https://ourfuturehealth.org.uk/research-programme/).

[7] The word diversity is used variably- to denote a range in ethnicity, racial categories, ancestral groups, age, gender, sexual orientation, language, education, access to care, socioeconomic status, social class, disabilities, geography, or any other shared characteristics in underrepresented populations. However, in the context of calls for diversity in genomics diversity is often used in relation to genetic ancestry (and how our ancestors migrated across the globe over millions of years).

scope of the genomic studies and clinical insights derived (Popejoy et al, 2020). That is to say, data diversification is often assumed to be complete if data is gathered from populations other than those with European ancestry. Referring to populations in a binary way as 'European or 'non-European' can suggest that they are homogeneous groups, ignoring the diversity within them and leading to a form of 'othering' (see Elias (2008)). Similarly, existing racial and ethnic categories often do not map to ancestral groups, -but are commonly used for recruiting diverse participants in genomics research. If we truly want to diversify genomic data, we must be more cognisant of the diversity that exists globally whilst closely interrogating the politics of classification.

2. Methodology

2.1 Aim and design

This review was designed to identify ethical, legal, and social issues that may arise from attempts to diversify data in genomic research, including any unintended consequences. To achieve this, a rapid review, incorporating elements of a systematic review, was conducted, and complemented with a narrative review. Greenhalgh, Thorne, and Malterud (2018) argue that systematic reviews are focused and have summative value, whilst the value of narrative reviews lies in their interpretative and critical stance designed to enhance understanding. Here, we aimed to draw on the strengths of both strategies.

2.2 Systematic rapid review

2.2.1 Search strategy

The PRISMA-S checklist was used to guide the literature search and ensure that all aspects of the process were reported thoroughly (Rethlefsen et al. 2021). An expert health librarian helped formulate the search strategy. Searches were conducted across both academic and grey literature (e.g., ethics reviews, regulatory and legal guidance, conference presentations) using the OVID Embase, The Social Science Premium Collection, and Web of Science databases. The thesaurus and free text search terms are detailed in Appendix A.

2.2.2 Inclusion criteria

We draw on Strech, Synofzik, and Marckmann (2008)'s Methodology, Issues, Participants (MIP) model and Butler, Hall, and Copnell (2016)'s guide to qualitative systematic reviews for outlining the inclusion/exclusion criteria. The inclusion criteria were developed iteratively with two researchers piloting the criteria on 30 abstracts to test and adjust eligibility. The review comprises papers that:

- report qualitative or quantitative empirical studies [Methodology]
- include as a primary or secondary focus diversity in genomic data (OR the inclusion of underserved groups in genomic/health studies), AND a primary or secondary focus on ethical, legal, and social issues as related to data diversification or the inclusion of underserved groups [issues]
- include populations considered historically underserved, racially or ethnically minoritised, or subject to on-going racial and/or intersectional disadvantage [population]
- were published between 1st January 2000 and the review date (26th February 2022)
- are published in English
- are readily available electronically through institutional subscriptions/direct from the author

2.2.3 Data collection and screening

The review was conducted collaboratively with team members piloting, discussing, and conducting the screening. With the aid of Covidence review management software, more than 7000 articles were screened against the inclusion criteria. Figure 1 provides an overview of the process, which included double screening 550 titles and abstracts, the removal of duplicates, and excluding articles deemed irrelevant. In total, 133 articles were included in the systematic rapid review (see Appendix B for full list).

Figure 1. Overview of the screening process

2.2.4 Data extraction

A data extraction template (Appendix C) was developed to capture metadata (e.g., country of study, study type, methodology and methods, study population) and content summaries which included higher level analysis of full articles (e.g. ethical, legal and social themes/subthemes, strengths and weaknesses, and lessons learnt), as well as a second round of analysis (e.g. key concerns voiced by study participants and author recommendations) of the data extracted strictly from the findings, discussion or conclusion sections. Each paper was reviewed by one researcher, allocated on the basis of their expertise.

2.2.5 Thematic analysis

All those involved in the review process met during the data extraction stage to discuss findings from included articles and identify high level codes. These codes were further developed as the data extraction process progressed. Codes were entered into Nvivo (v12) and populated with findings from the data extraction forms. Through a collaborative process, several iterations of the codes were developed. The first round of analysis resulted in codes that were added to the data extraction forms. Reviewers used these to collect data in the second round of analysis. The data from the second round of analysis was used to develop themes (Braun and Clarke 2012; 2021; Terry et al. 2022). These themes were presented at a '*Diverse Data Ethics*' workshop on 5th May 2022, which included an inter-disciplinary panel of experts identified during the screening of the literature and from existing networks.

2.2.6 Description of the reviewed studies

Studies included in the systematic rapid review employed qualitative, quantitative, or mixed methods approaches to explore the views of underserved groups, and discussed ethical, legal, and social issues around their participation in health or genomics research. Most of the studies engaged with the views of underserved groups, or ethnically or racially minoritised health professionals. Some studies proposed innovative qualitative methods for engaging with, or deliberating on, the views of underserved groups in research. Others analysed legal issues including legislation, procedures, and regulations in different regions. As displayed in Figure 2, most of the studies included in the systematic review were conducted in the United States (US).

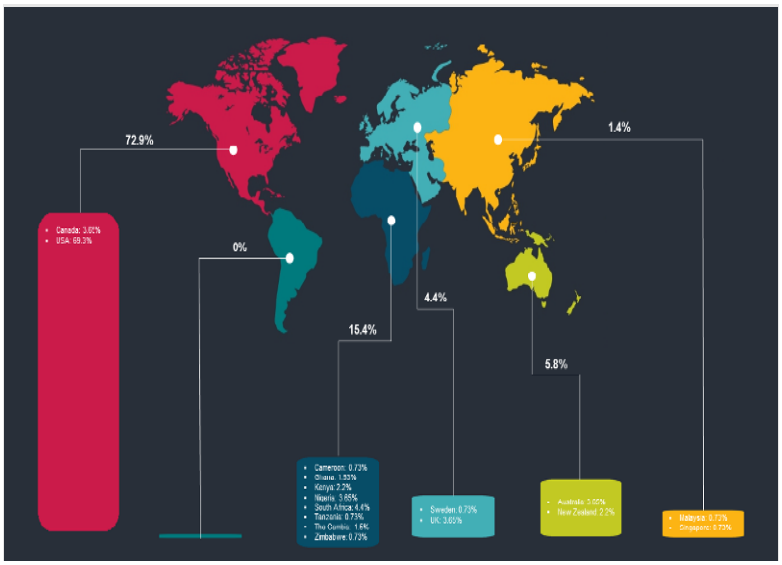

Figure 2. Distribution of origin of the papers analysed in the systematic review

2.3 Narrative review

The workshop discussion proved helpful in situating the reviewed material within wider debates. While our initial approach followed a systematic approach to a rapid review, as we explored and analysed the data generated it became apparent that restricting our reported findings purely to those identified within the articles found by our search strategy would not do justice to the complexity of this topic. Such issues do not necessarily rise to the surface of empirical research but may be embedded and hidden within research practices or wider social structures and systems. We found that key topics relating to the salience of wider structural issues were largely absent from the empirical literature, despite being crucial considerations in developing plans to diversify genomic datasets. In response, therefore, we adopted an analytical approach to draw out and examine these issues. As Greenhalgh, Thorne, and Malterud (2018) argue, narrative approaches have value over systematic reviews in that they provide interpretation and critique to deepen our understanding of complex issues. The 'Diverse Data Ethics' workshop catalysed this change in strategy from rapid review to expert-led narrative review, as it highlighted the extent to which critical discussion revealed the ethical issues otherwise opaque within the empirical studies.

The articles examined as part of the narrative review included conceptual, theoretical and review papers, including but not limited to, some of articles that were excluded from the systematic review, for example, in terms of issues and population.

2.4 Limitations

There are several limitations to the review. Firstly, in the rapid review we included studies with a focus on diversity/inclusion in relation to populations that could be considered historically underserved. This leaves out people who have been subject to other types of inequities, for

example, in relation to age, patients of rare disease, prisoners, children, and psychiatric patients amongst others. Secondly, due to time and budget constraints we had to limit the search to English language articles. Thirdly, Genomics England's primary focus is the English population and not many articles from England were captured and reviewed. However, there are valuable lessons to be learnt from the wider global literature, about respecting epistemological differences and working with globally underserved populations that have endured exclusion and inequities. Fourthly, many, though not all, of the reviews included in our study focused on issues associated with exploring diversity for genomic databases at a population level. We note that Genomics England samples were collected from patients presenting with rare diseases and cancer. The relationship between stigma, disease and culture will be different when research recruits from certain groups (e.g., diseases related to consanguineous relationships that may be associated with cultural stigma).

3.Findings: Key ethical, legal and social issues

3.1 Exclusionary research practices

Developing an understanding of the social, historical, and cultural context of a place before designing the research was suggested to be key to developing inclusive research (Segelov E. and Garvey G. 2020). This means being mindful of community perspectives, cultural norms, and beliefs as well as acknowledging and incorporating the experiences and expertise of local groups (Garrison N.A., Barton K.S., et al. 2019). Recognising diverse cultural values and establishing culturally competent systems of care is considered key in avoiding social harms (Segelov E. and Garvey G. 2020) and eliminating health inequalities (Matthews-Juarez P. and Juarez P.D. 2011). Cultural competency is described as the processes that inform healthcare professionals about the cultural factors and values of individuals and groups and incorporate them into the delivery and structure of the healthcare system to meet patients' diverse needs (Betancourt, Green, and Carrillo 2002). Cultural humility is used to emphasise the importance of reflexivity, active listening and taking responsibility for interactions (Isaacson 2014; Cuellar et al. 2008; Sabatello et al. 2019) in efforts to include participants from underserved groups in research (Sabatello M. 2019). The review suggests that many of the tools and practices commonly used for research fall short in cultural competency/humility and can be exclusionary. The following sections describe three ways in which this can happen.

3.1.1 Regulation obstructing ethical practices

The review highlighted a tendency for regulatory procedures to sometimes obstruct ethical approaches to data collection, analysis, interpretation, usage, and sharing. The challenge of developing appropriate methods for seeking consent from research participants was a recurring theme throughout the studies. Research ethics systems typically prioritise the individual

autonomy of research participants, and such an approach may not account for the community benefits and harms associated with the research which should also form part of consent processes (Tsosie, Yracheta, and Dickenson 2019; Jacobs B. et al. 2010). Indeed, several studies reported on the need for a more collective approach to decision-making, which is difficult to accommodate within traditional research ethics practices (Hiratsuka V.Y. et al. 2020; Abadie and Heaney 2015; Anie K.A. et al. 2021; Austin M.A. 2002). Where data collection initiatives are successful in recruiting diverse participants, the ability of prospective participants to evaluate the risks and benefits of taking part will be diminished if cultural nuances are not considered. For example, whether consent approaches should be familial, and community based as well as individual (Jacobs B. et al. 2010; Abadie and Heaney 2015; 2015), and when health literacy levels and epistemic inequalities (unequal access to learning) (Garrison N.A., Barton K.S., et al. 2019; Ridgeway et al. 2019) undermine the validity of consent.

Decontextualised regulatory and research ethics processes were seen as a barrier to addressing the specific cultural needs of communities during the process of research (Kraft S.A. and Doerr M. 2018), and in negotiating access (Tiffin 2019; Blanchard et al. 2020). In the absence of appropriate regulation, publicly sharing summary data of people from underserved groups may make them vulnerable to potential harms (Tiffin 2019). The adequacy of routine data management systems for maintaining privacy and anonymity of participants was another concern, particularly where privacy concerns pose a barrier to participation in genomic research for people from underserved groups (Amendola et al. 2018; Cohn E.G. et al. 2015; McDonald et al. 2012; Buseh A.G. et al. 2013; Simon, Tom, and Dong 2017; Oushy et al. 2015; Lee et al. 2019), and in relation to the potential for re-identification from summary data for small or geographically specific groups (Blacksher E. et al. 2021; Fatumo et al. 2022; Blanchard et al. 2020; Tiffin 2019). Studies also reported on individual and group concerns about the possible uses of data beyond the scope of the original research or by other research teams (de Vries J. et al. 2014; Schmidt C.W. 2001; Oushy et al. 2015; Halbert C.H. et al. 2016).

3.1.2 Research design often prioritises recruitment over engagement

The review highlighted the need to ensure that the research is designed in such way that is not exclusionary. For example, Kouritzin and Nakagawa (2018) suggest re-thinking efforts to promote inclusion in genomics research so that they become guided by data collection and analyses that are mutually beneficial to researchers and participants (Kouritzin and Nakagawa 2018). Research design more broadly has been criticised for reflecting what Bhambra (2017) refers to as methodological 'whiteness'- "a way of reflecting on the world that fails to acknowledge the role played by race in the very structuring of that world, and of the ways in which knowledge is constructed and legitimated within it" ((Bhambra 2017) in Rai et al. (2022, pp.4)). In their critical reflections about a study that formed part of a randomised control trial,

Rai et al. (2014) point to the ways in which standard approaches to, for example, participant recruitment, prioritise speed and volume of recruitment, with little scope for investing time in more community-based approaches centred on relationship building, especially with underserved groups.

Other practices critiqued in the literature include the over-emphasis on boosting recruitment from underserved groups as the primary means of diversifying data. Such approaches often employ strategies and tools from market research, such as demographic targeting (Epstein 2008; Cooper and Waldby 2014) with little regard to the body of literature that demonstrates the barriers to participation are more structural (see section 3.3). Moreover, such an emphasis on demographic targeting fails to respond to the challenges of categorisation (see section 3.3.3), or with the need to ensure potential participants feel empowered to engage in all aspects of the research process. Efforts to recruit diverse populations are often geared towards pre-defined goals and need to be complemented by meaningful engagement. Conflating recruitment with engagement can lead to further alienation of groups that are already impacted by historical injustices and consequently, have implications for trust (Ferryman and Pitcan 2018).

3.1.3 Lack of reflexivity in everyday research practices

The review emphasised the key role of reflexivity in avoiding exclusionary practices. Many papers highlighted the importance of reflecting on how everyday research practices can exacerbate inequalities. To help attend to this, Tervalon and Murray-García (1998) promote the notion of *cultural humility* which describes the practice of self-reflection. Minkler (2012, pp.6) describes this as: “learning our own biases, being open to others' cultures, and committing ourselves to authentic partnership and redressing power imbalances”. Practising such self-reflection can be especially challenging in genomic research where quantitative approaches dominate and data are commonly positioned as neutral. Salient examples of the ways in which research practice has either explicitly or unwittingly demonstrated a lack of cultural humility include: a lack of regard for genetic ancestry of the cell lines used in research; disrespect for participants’ cultural and spiritual beliefs; a lack of appreciation for traditional knowledge and practices; use of inappropriate or disrespectful language; and a lack of engagement with the socio-historical contexts that shape the lives of individuals or communities (Hull S.C. 2019; Lipphardt V. et al. 2021; Zaaijer and Capes-Davis 2021).

Furthermore, the development of appropriate communication strategies for the diverse cultural, linguistic and accessibility needs of participants is crucial in avoiding exclusionary practices (Halverson C.M.E. and Ross L.F. 2012; Rios et al. 2016; Shaibi et al. 2018; Sabatello et al. 2019; Garofalo et al. 2022). Lack of attention to this is not only detrimental to recruitment but can also lead to unrealistic expectations about any benefits or outcomes (Halverson C.M.E.

and Ross L.F. 2012; Beans J.A. et al. 2020; Lysaght T. et al. 2020). In genomic research, researcher and participant may conceptualise the research differently (Halverson C.M.E. and Ross L.F. 2012; Ridgeway et al. 2019). For example, Ridgeway et al (2019) reported that researchers spoke about scientific discovery whilst participants highlighted ancestral bloodline and ethical concerns. Such discrepant conceptualisations can adversely affect relationships of trust between (potential) participants and researchers and/or institutions, and exacerbate further underservice or health inequalities through the continued exclusion of underserved groups (Hudson M. et al. 2016; Culhane-Pera et al. 2017; Kraft S.A. and Doerr M. 2018; Dirks L.G. et al. 2019; Woof V.G. et al. 2020; Ta Park V. et al. 2021; Uebergang E. et al. 2021; Garofalo et al. 2022).

3.2 The importance of co-design

Many studies highlighted the importance of designing research with rather than on participants. Much can be learnt from research practice that prioritises co-design, with participants and researchers working collaboratively to create and set agendas, construct research questions, co-produce new knowledge and formulate plans for the ethical re-use of data. This requires recognising individuals from underserved groups as active researchers and knowledge producers. The literature demonstrated practical approaches and considerations for co-designing research (Blanchard et al. 2020; Kaladharan et al. 2021; Morgan J. et al. 2019). Studies emphasised the importance of sharing results with communities (Hiratsuka et al. 2012); mutually beneficial partnerships and transparency between investigators and communities (Beans J.A. et al. 2020); and being clear about the purpose of the research, as well as the engagement and recruitment activities (May et al. 2021). It was recommended that engagement is long-term and regularly evaluated (US National Academy of Medicine 2022). At the same time the literature pointed to the ethical, legal, and social issues generated when community engagement and participation are not valued or are poorly implemented and discussed some of the individual and group concerns that can potentially affect the design and implementation of community engagement practices.

3.2.1 Defining community engagement

Whilst the need for community engagement was a common theme in the papers we reviewed, we acknowledge that the term ‘community’ may need further problematizing than possible in this review. What constitutes a community and how might we address the very different types of communities we identify?

Furthermore, whilst community *engagement* in research is increasingly viewed as an ethical imperative (Moodley and Beyer 2019) there is little consensus about what it means in practice (Blasimme and Vayena 2016; Majumder et al. 2019). Ideally, community engagement is centred on the prioritisation of participants' needs and interests, recognising them as co-producers of knowledge (Nature Editorial 2022; Hutchinson and Sharp 2008; Bentley A.R., Callier S.L., and Rotimi C.N. 2020; Blanchard et al. 2020; Hiratsuka V.Y. et al. 2020; Anie K.A. et al. 2021; Bentley A.R., Callier S., and Rotimi C. 2019; Beans J.A. et al. 2020) and from collaboration between participants and researchers to co-design research from conceptualisation through to delivery (Hutchinson and Sharp 2008; Ridgeway et al. 2019; Shaibi et al. 2013; Abadie and Heaney 2015; Blacksher E. et al. 2021; Morgan J. et al. 2019; Nye 2019; Kraft S.A. and Doerr M. 2018). For example, working iteratively with individuals and groups to ensure any findings from genomic research are contextualised appropriately (Community engagement strategies were noted to enhance trust (Dirks L.G. et al. 2019)).

Many studies reported efforts to engage individuals and communities using a range of frameworks, models, and methods, often based on participatory practices. These included democratic deliberation; community-based dialogue using focus groups, interviews, workshops and/or discussions with community leaders or local organisations; and the development of relationship models based on issues of pertinence to participants (Anie K.A. et al. 2021; Beaton A. et al. 2017; Bonham, Citrin, et al. 2009; Culhane-Pera et al. 2017; Hendricks-Sturrup R.M. et al. 2021; Hiratsuka V.Y. et al. 2020; Dean C. et al. 2017; Dirks L.G. et al. 2019; Fatumo et al. 2022). However, such endeavours can also quickly become tokenistic and then run the risk of having the opposite effect, where researchers and their institutions define engagement rather than communities themselves(Moodley and Beyer 2019). Another problem is that community members will rarely have uniform needs and interests, yet engagement attempts often appear to assume group uniformity.

3.2.2 Exploitative research dynamics

A key step in co-design is attending to the hopes and fears of individuals within groups. Concerns from underserved groups about data use and exploitation were widely documented in the literature, which could impede recruitment efforts. Whilst the concerns may be similar for any population (Ridley-Merriweather K.E. 2018), for underserved populations these issues are likely to be exacerbated by experiences of stigmatisation, discrimination, and prejudicial judgements (Sabatello et al. 2019). For example, studies reported participants' concerns whether their data will become commodified and leave them dispossessed (Abadie and Heaney 2015); whether their data will be used in researchers' commercial ventures (Atkins et al. 2020; Beaton A. et al. 2017; Lee et al. 2019; Garrison N.A., Hudson M., et al. 2019); and whether others (e.g., governments) might attempt to utilise their data to discriminate further (Abadie and Heaney 2015). Other concerns included whether (and how) samples/data might be used beyond the scope of the original research or by different research teams (de Vries J. et al. 2014;

Garrison N.A., Hudson M., et al. 2019). These worries were heightened when they aligned with cultural beliefs that biospecimens contain the essence of the donor and need to be treated with care (Lee et al. 2019).

It was suggested that researchers from high income countries working with participants from poorer settings can create unfair/exploitative relationships (de Vries J. et al. 2014; Igbe M.A. and Adebamowo C.A. 2012). Studies also warned about practices that only involve local researchers in the research process when useful for participant recruitment. There are risks that funding and programs from developing regions are taken advantage of by researchers from high-income countries without proper commitment to capacity building and contributing to the larger objectives of local communities (Mulder N. et al. 2018) and that the full benefit of research was not always passed to the local community (Bentley A.R., Callier S.L., and Rotimi C.N. 2020). Concerns about "ethics dumping" - where privileged researchers outsource ethically questionable research activity to lower income or less privileged settings with less oversight - were also raised (Nature Editorial 2022). Understanding and attending to individual and group concerns is key in cultivating a research culture that facilitates co-design.

3.2.3 Understanding group as well as individual concerns

Efforts to diversify data and produce research that benefits underserved groups must consider the rights and interests of the group as well as those of individual participants. However, these may not always align. There are concerns within some communities about stigmatisation that might arise from genomic research in terms of diseases being linked to specific cultural groups (Faure et al. 2019; Ali-Khan S.E. and Daar A.S. 2010), or of being included in studies because of a certain trait (Abadie and Heaney 2015; Fatumo et al. 2022; Halbert C.H. et al. 2016; Lehmann L.S. et al. 2002; Garrison N.A., Hudson M., et al. 2019). Schulz, Caldwell, and Foster (2003, pp.165) noted that "*concerns…included the risk that the racial or ethnic group as a whole would become identified with one or more genetic condition and that this identification would lead to discrimination and further inequalit*y".

The potential harms from stigmatisation are felt immediately within groups, whereas the benefits of genomic research may take much longer to materialise (Beaton A. et al. 2017). Furthermore, even when the benefits of the research are more immediate, wider socioeconomic factors may affect people's ability to access those benefits (Schulz, Caldwell, and Foster 2003). For example, the organisational structure of healthcare services often acts to exclude many underserved groups (Halford et al. 2019), so that for example, targeted health interventions from genomic research- may be curtailed for these groups (Horowitz C.R. et al. 2019; Hammonds and Reverby 2019).

As a result, it is important that research ethics considers community concerns as well as individual concerns (Adashi, Walters, and Menikoff 2018; Gbadegesin and Wendler 2006;

Cragoe 2019; Buchanan and Miller 2006), as in some cases potential group harms may outweigh the benefits for individuals(Friesen et al. 2017; E. Emanuel and Weijer 2005). Understanding the concerns of communities as well as individuals can avoid disempowering and discouraging potential participants from actively engaging with the design and implementation of the research.

3.2.4 Data ownership and sovereignty

The concept of data (or biosample) 'ownership' is central to debates about both clinical and research repositories (Dickenson 2013). As Ballantyne (2020) argues, this is often used as a metaphor reflecting multiple concerns about data use and the disenfranchisement of participants in research. Different conceptualisations of ownership by underserved communities are important to consider (Garrison N.A., Hudson M., et al. 2019; Lee et al. 2019). Given that most legal systems consider there are no property rights in tissue samples (and the data derived from them) once donated, attention to alternative ways of conceptualising ownership may be helpful. Participants in genomic research may be encouraged to think of participation as an act of altruism, with their DNA donated as a ‘gift’ yet this conceptualisation may be problematic in the context of some cultural groups who have historically been disadvantaged and disenfranchised (Hutchinson and Sharp 2008). Attaching a monetary value to DNA could be used in some circumstances to reduce existing inequities (Abadie and Heaney 2015), and capacity building for more equitable benefit sharing (Bentley A.R., Callier S., and Rotimi C. 2019), particularly as biosamples and data are increasingly commercialised (Uebergang E. et al. 2021). Data sovereignty refers to the idea that data are subject to the laws and governance structures of the location in which they are collected. Rather than underserved communities handing over data sovereignty, attention should instead be directed to policies that facilitate participants’ control over their own data, and allow collective notions of ownership and benefit-sharing. Some examples of culturally-responsive data management practices that centre around Indigenous Data Sovereignty were highlighted (Hudson et al. 2020).

3.3 Wider structural issues

Understanding the reasons behind lack of diversity in genomic datasets, and any ethical, legal or social issues rising from efforts to address them, requires paying attention to the agency of the researchers and participants as well as the structural forces that may affect this agency.

This section details five structural issues surrounding data diversification that were highlighted in the reviewed literature and workshop discussions.

3.3.1 Data and technologies are not neutral

The biomedical research paradigm relies on positivist approaches that view science, and data, as neutral. Such approaches fail to acknowledge that data and technologies are socially constructed, and embed design decisions, assumptions, values, and ideologies that can be discriminatory and generate social harm (Benjamin 2019). For example, data often embed existing biases or reflect structural inequalities in society. Although not a new finding, this was a recurrent theme in the literature review and workshop, with calls to focus on what uses data are being put to instead of the creation of diverse datasets as a means to an end. We need to expose and remove the biases that are implicit within data as well as how practices can amplify these biases. What data we collect and how we categorise them is synonymous with what we value. Exploring these values (e.g., communities, justice, and equality), will allow the mapping of data collection onto an ethical framework, instead of 'collect first, then make more diverse'.

3.3.2 Legacies of colonialism, scientific racism, and perpetuating mistrust

A critical step in addressing lack of diversity in genomic data is through the inclusion of diverse participants. Although genomic medicine is a relatively young field it is situated within the historical trajectory of scientific racism (Reverby 2009; Elgabsi N. 2021).[8] Genetics has played a role in perpetuating racism (Roberts, 2011), and been invoked "to promote racist ideologies" (ASHG perspective 2018). For example, white nationalists have tried to use genetic ancestry and genetic testing to support their claims of racial superiority (see Harmon 2017; Panofsky and Donovan 2019).

Moreover, colonialism and past unethical research practices provide lasting legacies in which attempts to diversify genomic research must be contextualised (Blanchard et al. 2020; Buseh A.G. et al. 2013; Fatumo et al. 2022; Jacobs B. et al. 2010; Morgan J. et al. 2019; Kraft S.A. et al. 2018). An example of this is the Human Genome Diversity Project (HGDP) that aimed to explore global human genetic diversity. The project overlooked the potential social, financial, and cultural harms to Indigenous groups. This had lasting implications for trust in researchers, and the HGDP was criticised for resembling activities of European colonialists (Roberts, 2011;

[8] The Tuskegee Syphilis Study serves as a well-documented historical example. The Tuskegee Syphilis Study was a longitudinal study conducted by the United States Public Health Service in Tuskegee, Alabama, in which approximately 600 African Americans participated between 1932 and 1972. In 1972 it was revealed that the participants had received a dishonest explanation for their involvement in the research, and despite existing treatment for their condition- penicillin- they had been prevented from getting this treatment (Emanuel et al. 2008, pp.4), so that the research could continue. In response to the Tuskegee scandal in 1979 the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research by the US congress, issued the Belmont Report, highlighting respect for persons, beneficence, and justice as "the broader ethical principles [to] provide a basis on which specific rules may be formulated, criticised, and interpreted."

Dodson and Williamson 1999; Greely 2001; TallBear 2007; Claw et al. 2018).

It was noted that individuals from underserved groups are less likely to participate in biomedical research (Shim et al. 2022). Tied with legacies of colonialism, lack of trust in government or private institutions (Abadie and Heaney 2015; Canedo et al. 2020) and concerns about exploitation (Dirks L.G. et al. 2019) may contribute to lack of participation in genomic research (Bowekaty and Davis 2003; Drabiak-Syed 2010; Strickland 2006; Washington 2006).

Several factors were reported to exacerbate a lack of trust, including the inability on the part of researchers and institutions to acknowledge how historical injustices affected the perceived trustworthiness of a current venture. Acknowledging past injustices and learning from them was thought to be an important activity for researchers and institutions (Washington 2006; Smirnoff et al. 2018; White 2005; Walker E.R. et al. 2014)

However, lack of trust or willingness to participate in biomedical research, may not always explain the low rates of participation of underserved groups (Katz et al. 2007; 2008; Fisher and Kalbaugh 2011). Instead, structural issues such as lack of access to healthcare services where recruitment in biomedical research occurs, or biased assumptions made by healthcare professionals about the willingness of individuals from underserved groups to participate in studies may provide better explanations (Shim et al. 2022; Fisher and Kalbaugh 2011). Underrepresentation might also result from structural issues such as a need for translation services to be able to recruit participants from diverse backgrounds.

Thus, there are concerns that decades of structural inequalities leading to a lack of diversity in genomic data may be perpetuated unless we take proactive steps to address them.

3.3.3 Issues in the categorisation in genomic datasets and their consequences

This review stems from concerns that racial and ethnic minorities are underrepresented in genomic datasets but there are also inherent risks in using these categorisations to examine issues of underrepresentation. Genomic diversity does not map onto race or ethnicity- which are social constructs, and racial or ethnic categories used for data collection do not map onto ancestral groups in genomic data. In fact, there are more genomic variations within groups rather than between groups (Tishkoff and Kidd 2004). As a result, whilst common racial and ethnic categories are helpful for studying health inequalities, they often do not help in studying genetic variation across populations. Genomic medicine is increasingly concerned with developing more sophisticated ways of categorising populations that can mitigate these issues (Gurdasani et al. 2019).

Categorisation and classification of genomic data may have some clinical relevance, for example, from a clinical perspective it is useful to be aware that genetic conditions are more common in people with certain ancestry than others (Kariuki and Williams 2020), but such

differences are rarely absolute and too much focus on such information may lead to the condition being missed in populations in which it is often rare. Common racial, ethnic, and gender categories can lead to opportunities for researching health inequalities to drive change towards reducing them. However, such groupings may bear no relation to how individuals conceive of their own intersectional identities and their sense of connection to, or affiliation with, different groups or communities (see also Weller (2010)). This can render incorporating any forms of collective engagement in a study challenging, particularly in diverse settings such as the UK.

Understandings and meanings applied to race, ethnicity and ancestry terminology come with historical legacies of colonialism and the tensions from configurations of power, sovereign authority, and the vulnerability of different subject-populations (Sheth 2009), which are rarely conceptualised in studies (Bonham, Sellers, et al. 2009; Bonham, Green, and Pérez-Stable 2018; Birney et al. 2021; Khan et al. 2021). While the use of these terms is evolving (Flanagin et al. 2021; Khan et al. 2021), differences in when, where, and how they should be used remains (Lujan and DiCarlo 2018; Hunt and Megyesi 2008). There is a tendency to use genetic (biogeographical) ancestry and ethnicity/race interchangeably (Conomos et al. 2016), leading to conflation between socially constructed notions of race and ethnicity that are tied to identity and biological categories of ancestry (Armitage 2020). This is problematic because social classifications are not an adequate descriptor of the distribution of genetic variation in humans and furthermore, as described above, there is often greater genomic variation within groups than between them (Tishkoff and Kidd 2004). Furthermore, using these categories within genetic studies risks inviting misinterpretation that race and ethnicity are themselves biological.

The use of genetic ancestry categories over racial or ethnic categories helps to some extent; however, problems remain in that often categories are mapped back onto the racialised social world (Wade et al. 2015). For example, comparative references to genetic ancestry that are clustered continentally can end up reinforcing an illusion that racial categories are biological (reifying racial categories) or increase the likelihood of stereotyping (A. C. F. Lewis et al. 2022). This language slippage has been reported by Fujimura and Rajagopalan (2011) in their ethnographic research of GWAS and interviews with GWAS researchers. They emphasised that clusters of genetically similar samples were sometimes described as samples with ‘shared ancestry’, whilst all humans share an ancestry.

Rather than diversifying data by simply recruiting greater numbers, papers called for consideration of how data are collected, categorised and classified *with* populations rather than *for* populations. This requires appropriate community engagement before, during and after research (Majumder et al. 2019) as detailed in section 3.2.

3.3.4 Balancing researcher priorities with participant/individual/group priorities

Certain research ideas may be founded on problematic assumptions about the interests and priorities of underserved groups without engaging meaningfully with the priorities of those involved (Weijer and Anderson 2002; Boyer B.B. et al. 2011; Hiratsuka V.Y. et al. 2020; Hiratsuka V., Brown J., and Dillard D. 2012). For example, in reflecting on research with Indigenous Canadians, Morgan J. et al. (2019, pp. 408) argue that "*... the perpetration of colonial research practices, even when well intentioned, continues to marginalise Indigenous groups through Western ethnocentric interpretation of their 'needs'*". It may be that genomics research is not a priority for individuals and communities, in comparison to other more pressing healthcare needs (Munung, Mayosi, and de Vries 2018; Nye 2019; Hiratsuka V.Y. et al. 2020). Goldenberg A.J. et al. (2013, pp. 425) draw on Fine, Ibrahim, and Thomas (2005) and Sankar et al. (2004) to suggest that "an overemphasis on genetic determinants might lead researchers to ignore important social or environmental contributions to health inequalities and might promote a disproportionate reliance on downstream medical interventions at the expense of upstream social or political change". Neglecting the priorities of individuals and groups can exacerbate issues of (mis)trust (Hiratsuka V.Y. et al. 2020; Segelov E. and Garvey G. 2020), especially when genomic services are not affordable or covered by healthcare systems (Hiratsuka V.Y. et al. 2020). Various studies called for transparency and impartiality about decisions on research priorities (Blacksher E. et al. 2021; Weijer and Anderson 2002; Hiratsuka et al. 2012; Garrison N.A., Hudson M., et al. 2019).

3.3.5 Unsupportive environment for a diverse workforce

Moving towards more equitable and fair genomics research requires diversifying the workforce as well as the data (Bonham V.L. and Green E.D. 2021). The literature highlighted the need to move beyond tokenistic approaches, simply appointing a diverse workforce is not enough and a supportive environment to sustain the diversity is needed (Lee et al. 2019). For example, Jeske M. et al. (2022) studied three US based precision medicine research consortia and found tokenistic tendencies in recruiting underrepresented team members that often aimed to increase the diversity of study participants, whilst allowing existing power structures and hierarchies in the academic research ecosystem to limit the influence of these team members in the study design.

The literature also reported on concerns regarding the tendency to overburden health professionals from underserved groups with the responsibility for addressing them. This is problematic because it failed to acknowledge this issue as intrinsically structural and institutional. For example, while (Taylor J.Y. and Barcelona de Mendoza V. 2018) champion nurse scientists from underserved backgrounds the authors point to greater expectations for these nurse scientists, without acknowledgement of the wider contexts within which the issues are situated. Appointing equality, diversity, and inclusion (EDI) leads who identify as part of an

underserved population often leads to this person being tasked with tackling oppression and racism within the institution (Ahsan 2022). This role therefore can become a 'trap' whereby the EDI worker fails due to resistance when exposure of problems results in shame and discomfort for the institution. Incentive structures to cultivating and rewarding true diversity are needed.

4. Discussion

This review has examined the literature that focussed on ethical, legal and social issues associated with attempts to diversify data in genomics research. However, ensuring diversity and improving representation in data may not always be more ethical or equitable when treated as the endpoint, with past research highlighting how such intentions might paradoxically perpetuate health inequalities.

The need to position ethics at the forefront of such endeavours is clear and must precede the technicalities of research design, collection, and processing data. Gaining research ethics approval will often be insufficient to being ethical in this sense. Many articles showed the shortcomings of neo-liberal, centralised, compliance-oriented approaches to ethics that reduce ethical considerations to risk assessment and the acquisition of "informed consent." This is not to say that regulatory procedures, or indeed consent processes, do not have a place, but rather, they are only part of the business of being ethical in research.

Ethical issues are ontological and epistemological issues that raise important questions about what we know and how we know it. Much can be gained from drawing on approaches that prioritise everyday ethical issues and strive for more just and equitable research practices. Examples include disability, race and feminist care ethics. These approaches have more relational and situated emphases which could, for example, attend to the ethical issues raised for/by an individual participant or family, or focus on understanding the implications of systemic issues such as institutional racism.

Ethical *preparedness* is key to navigating the ethical, legal, and social issues surrounding the diversification of genomic data. Ethical preparedness is concerned with the ability and willingness to work in morally appropriate ways. In practice, this means forsaking notions of

universal, ‘off the shelf’ solutions to ethical issues. It also involves resisting the dominance of regulatory and procedural approaches, including the over-reliance on consent as a means of managing ethical risks (Lyle et al. 2022). Rather, emphasis is placed on creating spaces, and providing the resources and support necessary to empower researchers to work through ethical issues as they arise (Samuel et al.2022). To facilitate ethical preparedness there needs to be a significant and effective cross-fertilisation of ideas between those who are ‘doing the work', those for whom the work is being done, and those who theorise or conceptualise about it (Farsides and Lucassen Submitted).

The review also highlighted the importance of up-front consideration of how research endeavours intended to diversify data or promote inclusion are conceived and conducted. This involves moving the debate beyond recruitment of individuals from underserved groups as the endpoint, to attend to issues of equity and justice throughout the research process. Ethical practice must, therefore, be foregrounded in research design.

Important here are the potential misalignments between the agendas and priorities of research institutions, researchers, and participants. The technical aspects of genomics are often separated from the ethical, legal, and social landscape in which it is situated. We suggest that ethics needs to be incorporated into everyday research practices from their conception to data collection, analysis, and dissemination. Measures towards improving cultural humility and reflexivity in research, employing more inclusive methods, considering community concerns and priorities, and annotating the datasets available for re-use with the context(s) in which data were collected needed to be addressed. Adopting such measures can enable researchers to understand the ethical, legal, and social landscape of genomics beyond procedural approaches. At the institutional level, responsible procedures and practices to curate data and metadata must exist in order to prevent potentially abusive or exploitative practices (Lipphardt V. et al. 2021) or to provide pipelines that allow annotation of the datasets with the context(s) in which data were collected to improve ethical approaches to data re-use.

The literature emphasised the crucial role of co-design in conducting ethical research with people from underserved groups. Engagement and on-going dialogue with participants in all stages of the research from conception and developing research priorities, to dissemination, policy co-development and co-governance is key (NIHR INVOLVE Advisory Group 2018). As a result, co-design may involve identifying individual and group concerns, discussions, negotiations and making decisions about best approaches for identifying research priorities, data collection, primary and secondary usage, power sharing, benefit sharing, plans for long term data sharing and negotiating the ownership of data and infrastructures.

More comprehensive and reflexive descriptions on the part of researchers about their community engagement, and classifications/categorisations used for data collection and analysis are important steps. The drive towards improving research integrity has inspired some

medical journals such as the Lancet, to reject papers that do not acknowledge local researchers and collaborators, recognising this as a breach of research integrity (Waruru 2022). Similarly, Nature encourages journal authors, editors and reviewers to adhere to a global "inclusion and ethics" code of conduct for "developing, conducting, reviewing and communicating research" (Nature Editorial 2022). This includes communicating if local researchers have been involved in all stages of the research process and requires detailing plans for benefit sharing, capacity building for local researchers, and assessing if the research might lead to stigmatisation or discrimination for participants amongst other questions (Nature Editorial Policies on Authorship 2022).

Redressing the over-representation of European populations in data repositories will require a shift of focus towards diverse knowledge-making; knowledge making that takes account of the context in which genomic findings are made; and in which potential participants are understood as active researchers and knowledge producers. We also need to diversify disciplinary practices and move away from the concept that data are neutral. Regarding data as socially constructed re-positions the focus to consider why and how data are generated, by/for whom, and the processes through which data are translated into knowledge.

Diversifying data is rife with challenges relating to the lack of clarity around concepts central to the debate (such as diversity and community), and with constructing categories used to delineate those deemed as either over- or under-represented in data sets. A focus on the production of diverse knowledge does not detract from these challenges, but rather, shifts emphasis to working with individuals and communities to ensure that the generation and interpretation of data attends to the priorities and concerns of those involved, and is understood within the cultural, economic, political, and social context.

Consideration of the ongoing use of material in genomic repositories is important. There is a danger that researchers will be unaware of, or deterred from using any new, more heterogeneous data sets due to a perception that homogenous datasets are always the better set to use from a scientific perspective. In practice this may mean- for example- journal reviewers paying attention to whether data from underserved groups have been excluded from a data set for good reason. Any focus on diversifying knowledge, therefore, needs to consider potential challenges at all stages of the research process including future re-uses of data.

Examining how research environments, methodologies and technologies, infrastructures, local and international networks, and the interaction between all these actors can lead to inequitable outcomes is key. It is only with such holistic approaches to diversification that genomic medicine can become globally relevant.

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Appendix A

The thesaurus and free text search terms employed on 26th February 2022

Web of Science – All Databases

https://www.webofscience.com/wos/alldb/summary/86edc3a0-7bfe-4de5-9f6a-a843ba62dd3d-260f0a4f/relevance/1

((genom* OR exom* OR "precision medicine" OR "personalised medicine" OR "personalized medicine" OR biobank*) AND (admix* OR ethnic* OR minorit* OR ancestr* OR race* OR racial* OR "biological* construct*" OR "social* construct*" OR divers* OR inclus* OR representativ* OR under-represent* OR underrepresent* OR under-serv* OR underserv* OR generalisab* OR generalizab*) AND (inequal* OR justic* OR ethic* OR equit* OR racis* OR "Health disparit*" OR "health care dispar*" OR legal*))

Embase 1974 to present

https://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=7UMsdfYFrTNOAgJ7zmAnTMMMJ5Xp2lhXJFzrKHmiNfDpvHMo2Mr4SNzYOrK6UfMc6

1 exp genomics/ or personalized medicine/ or exp population genetics/ or exp precision medicine/209248
2 (genom* or exom* or "precision medicine" or "personalised medicine" or "personalized medicine" or biobank*).ti,ab.915843
3 1 or 21013531
4 (admix* or ethnic* or minorit* or ancestr* or race* or racial* or "biological* construct*" or "social* construct*" or divers* or inclus* or representativ* or under-represent* or underrepresent* or under-serv* or underserv* or generalisab* or generalizab*).ti,ab.1953891
5 exp ancestry group/ or exp ethnicity/ or exp ethnic group/ or exp racial identity/ or exp racial diversity/ or exp genetic variation/ or exp racial groups/589662
6 4 or 52300589
7 ("health care dispar*" or "health* dispar*" or intersectional* or justic* or ethic* or inequal* or racis* or legal* or equit*).ti,ab.426784
8 exp health care disparity/ or exp health disparity/ or exp racial disparity/ or exp social class/ or exp social justice/ or exp ethics/ or exp racism/ or exp law/513622
9 7 or 8776000
10 3 and 6 and 93938
11 103938
12 exp plant genetics/ or exp animal genetics/16542
13 11 not 123934
14 limit 13 to yr="2000 -Current"3850

ProQuest Social Science Premium Collection

(MAINSUBJECT.EXACT("Genomics") OR ab(genom* OR exom* OR "precision medicine" OR "personalised medicine" OR "personalized medicine" OR biobank*) OR ti(genom* OR exom* OR "precision medicine" OR "personalised medicine" OR "personalized medicine" OR biobank*)) AND ((MAINSUBJECT.EXACT("Ethnicity") OR MAINSUBJECT.EXACT("Minority & ethnic groups") OR MAINSUBJECT.EXACT("Racial identity")) OR ab(admix* OR ethnic* OR minorit* OR ancestr* OR race* OR racial* OR "biological* construct*" OR "social* construct*" OR divers* OR representativ* OR under-represent* OR underrepresent* OR under-serv* OR underserv* OR generalisab* OR generalizab* OR inclus*) OR ti(admix* OR ethnic* OR minorit* OR ancestr* OR race* OR racial* OR "biological* construct*" OR "social* construct*" OR divers* OR representativ* OR under-represent* OR

underrepresent* OR under-serv* OR underserv* OR generalisab* OR generalizab* OR inclus*)) AND ((MAINSUBJECT.EXACT("Health disparities") OR MAINSUBJECT.EXACT("Social justice") OR MAINSUBJECT.EXACT("Ethics") OR MAINSUBJECT.EXACT("law")) OR ab("health care dispar*" OR "health* dispar*" OR intersectional* OR justic* OR ethic* OR inequal* OR equit* OR racis* OR legal*) OR ti("health care dispar*" OR "health* dispar*" OR intersectional* OR justic* OR ethic* OR inequal* OR equit* OR racis* OR legal*))
Limited to 01/01/2000 to 26/02/2022
English only

Appendix B

Papers included in the review

1. Abadie, R. & Heaney, K. 2015. "We can wipe an entire culture'': Fears and Promises of DNA biobanking among Native Americans. 39**,** 305-320.

2. Adana, A. M. L., Young, G. S., Ryan, B., Lengerich, E. J., Aumiller, B. B., Dignan, M. B. & Paskett, E. D. 2018. Predictors of Willingness to Participate in Biospecimen Donation and Biobanking among Appalachian Adults. 29**,** 743-766.

3. Akinyemi, R. O., Akinwande, K., Diala, S., Adeleye, O., Ajose, A., Issa, K., Owusu, D., Boamah, I., Yahaya, I. S., Jimoh, A. O., Imoh, L., Fakunle, G., Akpalu, A., Sarfo, F., Wahab, K., Sanya, E., Owolabi, L., Obiako, R., Osaigbovo, G., Komolafe, M., Fawale, M., Adebayo, P., Olowoyo, P., Obiabo, Y., Sunmonu, T., Chukwuonye, I., Balogun, O., Adeoye, B., Oladele, F., Olowoniyi, P., Adeyemi, F., Lezzi, A., Falayi, A. T., Fasanya, M., Ogunwale, K., Adeola, O., Olomu, O., Aridegbe, O., Laryea, R., Uvere, E., Faniyan, M., Melikam, E., Tagge, R., Akpa, O., Akinyemi, J., Arulogun, O., Tiwari, H. K., Ovbiagele, B. & Owolabi, M. O. 2018. Biobanking In A Challenging African Environment: Unique Experience From The Siren Project. 16**,** 217-232.

4. Ali-Khan, S. E. & Daar, A. S. 2010. Admixture Mapping: From Paradigms Of Race And Ethnicity, To Population History. 4**,** 86.

5. Anie, K. A., Olayemi, E., Paintsil, V., Owusu-Dabo, E., Adeyemo, T. A., Sani, M. U., Galadanci, N. A., Nnodu, O., Tluway, F., Adjei, D. N., Mensah, P., Sarfo-Antwi, J., Nwokobia, H., Gambo, A., Benjamin, A., Salim, A., Osae-Larbi, J. A. & Ofori-Acquah, S. F. 2021. Sickle Cell Disease Genomics Of Africa (Sicklegenafrica) Network: Ethical Framework And Initial Qualitative Findings From Community Engagement In Ghana, Nigeria And Tanzania. 11**,** E048208.

6. Atkins, R., Kelly, T.-A., Johnson, S., Williams, W., Nelson, Y., Joseph, P. V., Jackson, D., King, D., Stellmacher, T., Halty, N.-D., Tinglin, M. & Gage, G. 2020. Eliciting Willingness And Beliefs Towards Participation In Genetic Psychiatric Testing In Black/African American Mothers At Risk For Depression. 10.

7. Austin, M. A. 2002. Ethical Issues In Human Genome Epidemiology: A Case Study Based On The Japanese American Family Study In Seattle, Washington. 155**,** 585-592.

8. Avera, E. 2009. Rationalisation And Racialisation In The Rainbow Nation: Inequalities And Identity In The South African Bone Marrow Transplant Network. 16**,** 179-193.

9. Balasopoulou, A., Mooy, F. M., Baker, D. J., Mitropoulou, C., Skoufas, E., Bulgiba, A., Katsila, T. & Patrinos, G. P. 2017. Advancing Global Precision Medicine: An Overview Of Genomic Testing And Counseling Services In Malaysia. 21**,** 733-740.

10. Beans, J. A., Woodbury, R. B., Wark, K. A., Hiratsuka, V. Y. & Spicer, P. 2020. Perspectives On Precision Medicine In A Tribally Managed Primary Care Setting. 11**,** 246-256.

11. Beaton, A., Hudson, M., Milne, M., Port, R. V., Russell, K., Smith, B., Toki, V., Uerata, L., Wilcox, P., Bartholomew, K. & Wihongi, H. 2017. Engaging Maori In Biobanking And Genomic Research: A

Model For Biobanks To Guide Culturally Informed Governance, Operational, And Community Engagement Activities. 19**,** 345-351.

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14. Bentley, A. R., Callier, S. & Rotimi, C. 2019. The Emergence Of Genomic Research In Africa And New Frameworks For Equity In Biomedical Research. 29**,** 179-186.

15. Bentley, A. R., Callier, S. L. & Rotimi, C. N. 2020. Evaluating The Promise Of Inclusion Of African Ancestry Populations In Genomics. 5**,** 5.

16. Blacksher, E., Hiratsuka, V. Y., Blanchard, J. W., Lund, J. R., Reedy, J., Beans, J. A., Saunkeah, B., Peercy, M., Byars, C., Yracheta, J., Tsosie, K. S., O'leary, M., Ducheneaux, G. & Spicer, P. G. 2021. Deliberations With American Indian And Alaska Native People About The Ethics Of Genomics: An Adapted Model Of Deliberation Used With Three Tribal Communities In The United States. 12**,** 164-178.

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Appendix C

Data extraction template

	Reviewer Name
Article ID	
Title	
Country in which the study conducted	
Study tags	
Study type	
Did the study use any of the following words in the introduction section (Diversity, inclusion, representation, generalisability)	(if so, then please answer the following question)
Did the study define it?	
Please add quote to support your responses for the study introduction questions above.	

What were the community's concerns about participation? (Why they were reluctant to participate?)	1. Discrimination 2. Privacy 3. Stigmatisation 4. Sovereignty 5. Data sharing 6. Data usage 7. Benefit sharing 8. Commercial interest 9. Objectification and commodification 10. Data ownership 11. Exploitation 12. Inequalities in access 13. Monopoly on knowledge making 14. Social status 15. Noone like me in the research team 16. Cultural norms 17. Individual/group/tribe dynamics 18. Misconceptions about genomics research 19. Public/private relationships 20. Lack of trust due to past unethical research/practices 21. Genomics not a priority for the community 22. Other
Please add quotes from the study to support your response to the question above.	
Did the study explore/assess whether genomic research/medicine was a priority to the community?	
What does the article discuss in relation to findings?	

What does the article recommend should be done?	1. Better community engagement 2. Less binary divide between researchers/communities 3. More interdisciplinarity 4. Improve cultural competency 5. More investment in community infrastructure/expertise 6. Diversity in workforce 7. More training for scientists 8. Better science communication to communities 9. Better governance mechanisms 10. Better consent models 11. Fairer distribution of benefits 12. Assessing community priorities 13. Other
Diversity/inclusion	
ELSI	
Methodology	Qualitative/Quantitative
Methods	
The target group	
Key Themes	
Sub Themes	
Weakness	
Strength	
Lessons learnt	

Appendix D- Authorship of this report

All stages of review and report

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Review + Analysis

Dr Luiz Valerio De Paula Trindade
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Nechama Tatz-Wieder, University of Oxford
Tess Johnson, University of Oxford
Florence Robinson Adams, University of Cambridge
Yoseph Eskandar, University of Oxford
Dr Elizabeth Redrup, PHG Foundation
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Vicky Fenerty, University of Southampton

Workshop Experts (many also commented on early drafts of the report)

Prof Donna Dickenson. University of London
Dr Jenny Douglas. Open University
Prof Emma Kowal. Deakin University (met with FH separately)
Dr Alice Popejoy. UC Davis
Dr Maya Sabatello. Columbia University
Krystal Tsosie. Vanderbilt University
Dr Arzoo Ahmed. Genomics England
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Dr Padraig Dixon. University of Oxford
Alison Hall. PHG Foundation
Dr Maxine Mackintosh. Genomics England
Dr Colin Mitchell. PHG Foundation
Lyra Nightingale. Genomics England
Prof Catherine Pope. University of Oxford
Prof Jenny Reardon. University of California
Dr Natalie Banner. Genomics England