Addressing Ethnic Health Inequities by Improving the Inclusiveness of Digital Health Research for South Asians

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Abstract

South Asians are one of the largest ethnic minority groups in the United Kingdom. They face the multi-faceted burden of higher prevalence of long-term health conditions, worse access to health services, and poorer health outcomes. With the increase in digitally enabled health services, it is important to ensure that digital health apps are helping to address existing ethnic health inequities instead of creating new or exacerbating existing ones. Therefore, we need to engage with South Asians (SAs) early on and widen their participation in digital health research. However, there are several barriers to doing this effectively. Based on their experience of engaging with South Asians for developing and evaluating four health apps, the authors recommend technology developers and health researchers to understand the cultural context of common health behaviours of South Asians, and then consider the accessibility features of digital health apps and inclusivity of research procedures. This will contribute to making digital health research more inclusive for South Asians, and ultimately to reducing ethnic health inequities.

Introduction

Health inequities have always existed, but the extent to which they emerged and were discussed during the COVID-19 pandemic, was exceptional. The World Health Organization (WHO) defines health inequities as *'avoidable differences in health status or the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age'* (**World Health Organisation, 2018**), with these differences also often being considered unfair (**Williams et al., 2022**).

There are many ways in which health inequities can be introduced and exacerbated. Commonly, they are related to social determinants of health, such as age, gender, income, education, employment, and housing (**Dahlgren & Whitehead, 2021**), while these determinants themselves are often interrelated and impact different individuals and groups differently. That is why, the intersectional approach to health inequalities highlights cumulative and additive effects of different categories of disadvantage (**Graham et al., 2011**) on an individual or a sub-group within a particular disadvantaged group. For example, first-generation immigrant women to a country may face additional barriers because of their poor digital and health literacy than second-generation immigrant women. In addition, health inequities are associated with higher costs: one-fifth (i.e., £4.8 billion) of the total National Health Service (NHS) hospital budget is spent in England's most deprived communities (**Asaria et al., 2016**), and £29.8 billion is lost to the country's economy annually because of lost productivity in these communities (**All-Party Parliamentary Groups, 2022**).

Ethnic Health Inequities

Ethnic health inequity is a particular type of health inequity. According to a report commissioned by the NHS Race and Health Observatory, people from ethnic minority groups continue to experience inequities in healthcare access and health outcomes, compared to their white counterparts (**Robertson et al., 2021**), and the most at-risk groups experience socioeconomic deprivation. Health inequities are significantly higher in Greater Manchester than the rest of the country, with life expectancy approximately two years less than the England average. Greater Manchester is an ethnically diverse region, where more than half of the ethnic minorities are South Asians (**Manchester City Council, 2021**), consisting mainly of Indian, Pakistani and Bangladeshi. South Asians are

most likely to live in deprived areas (**Ministry of Housing Communities and Local Government, 2020**), have shown more disparities in health outcomes than others (**Harries et al., 2019; Watkinson et al., 2021; Public Health England, 2018**) and are under-represented in clinical studies in Greater Manchester (**Abel et al., 2023**).

Moreover, the COVID-19 pandemic exacerbated ethnic health inequities for South Asians living in deprived areas, which was demonstrated through higher rates of mortality attributed to COVID-19, compared to those living in least deprived areas (**Kontopantelis et al., 2021**). Bangladeshi and Pakistani males also had the highest mortality rate due to COVID-19, which is 2.7 and 2.2 times higher than White/British males, respectively (**Office for National Statistics, 2022**).

Ethnic health inequities are a complex and multi-dimensional problem. Among South Asians, the problem is demonstrated through a higher prevalence of long-term conditions, increased likelihood of developing such conditions (e.g., cardiovascular, kidney, musculoskeletal, diabetes etc.), and reporting poorer self-reported health (**Raleigh 2023; Pati et al., 2015**). Despite this multi-faceted burden, resource allocation is not proportionate to the overall productivity loss and NHS hospital costs associated with managing these long-term conditions.

Ethnicity and culture

Ethnicity is a dynamic social construct that is commonly used to describe distinct populations and is reported in research, though with inconsistency and in a less systematic way. However, to understand and address ethnic health inequities at the individual level we should be focusing more on culture, which is a multi-faceted and subjective identity which people use to define themselves (**Weiss, 2003**). Culture has a strong influence on people's health-seeking and treatment adherence behaviours, which can subsequently result in poor treatment and health outcomes (**Thomson et al., 2021**). For example, pain terminologies, which are not culturally attuned, may result in wrong or non-use of digital pain self-reporting tools. This reporting issue may then translate into wrong interpretation of pain self-reports and decision making by healthcare professionals, hence poor pain treatment outcomes. Although we acknowledge the enormous complexities around culture (**Nazroo, 2008; Nazroo et al., 2019**) and its influence on health behaviours and access to healthcare services (**Dixon-Woods et al., 2006**), in the context of our work we are considering culture as intra- and inter-personal factors that shape ethnic groups' beliefs, attitudes, and behaviours. Referring to inequities related to people's ethnic and cultural background, we will use *ethnic health inequities* as a term to avoid any confusion.

Digital Health Inequities Among South Asians

Digital health technologies

The UK's National Health Service envisioned digitally enabled healthcare services to reduce existing health inequities (**NHS, 2019**). However, it is also recognised that digitisation of services may have negative impacts on certain groups (**Wadhawan, 2023**). Evidence also suggests that South Asians may find it challenging to use digital health technologies within the healthcare system (**Aldosari et al., 2023; Hyman et al., 2022**), and their adoption of digital health apps is also low. As a result, introducing digital health technologies (including health apps) in the healthcare system may exacerbate the existing ethnic health inequities.

Under-representation of South Asians in health research

There is no simple solution to the problem of ethnic health inequities. However, widening participation through efforts and initiatives aimed at increasing the diversity and inclusion of individuals or groups in health research is the first basic step. This would enable researchers to understand the problem, find possible answers to it, as well as develop and test digital health interventions with South Asians (SAs) to address inequities. SAs are widely under-represented in many domains of health research such as cardiovascular (**Khunti et al., 2017**), hypertension (**Lip et al., 2022**), and musculoskeletal disorders (**Njobvu et al., 1999**). For managing long-term conditions, many digital health tools are being developed and tested, but participation of SAs in development and evaluation of these technologies has remained poor. Possible reasons for this might be misconceptions associated with some groups being 'hard-to-reach', hence creating barriers to engaging with these communities, and inviting their participation in research. It has been reported in the literature that researchers have negative attitudes that impact their decisions about which groups to recruit, such as that some ethnic minority groups may not be able to keep appointments or comply with the study protocol due to poor English language skills and inadequate transport (**Lo & Garan, 2008; Redwood & Gill, 2013**). The *publish-or-perish* culture within academia may further create barriers to engaging diverse participant samples, as research may be rushed to meet tight recruitment deadlines, meaning that researchers instead focus on populations who are perceived as 'easier' to recruit. In this regard, the NIHR's (National Institute for Health and Care Research) INCLUDE ethnicity framework is a useful guide for health researchers to plan clinical research carefully (**Treweek et al., 2021**).

This under-representation in health research and limited external validation have led to a misalignment between healthcare service delivery and the SA context of disease and health (**MacNeill et al., 2013**). Ethnic

health inequities may stem from non-inclusive research (**Osuafor et al., 2021**) and lack of the SA-specific evidence, thus healthcare commissioners in England have given little attention and showed limited confidence to address the issue of ethnic inequities (**Salway et al., 2016**).

Recommendations for making digital health research more inclusive for South Asians

To address ethnic health inequities with the use of digital health tools, it is important to widen participation from SAs in research, but this is challenging within the context of existing research procedures and practices. Our recommendations are for researchers, technology developers and public and patient involvement professionals to facilitate bringing about the change in existing research practices, however, we acknowledge that sustaining and institutionalising these changes would require understanding and addressing higher level structural barriers.

Acknowledging the diversity, we have been engaging with Pakistani communities living in Greater Manchester in a variety of research activities (i.e., public involvement group meetings, interviews, focus group discussions and individual interaction with community gatekeepers). The purpose of community engagement was to develop accessible and culturally acceptable digital health apps and to evaluate them in health and social care contexts. Our collaborative work with these communities has helped us learn about the barriers to ethnically inclusive health research and accessibility and acceptability of health apps, as well as ways to overcome them. These health apps are:

(a) *Manchester Digital Pain Manikin*, a digital pain self-reporting tool (**van der Veer et al., 2020**)
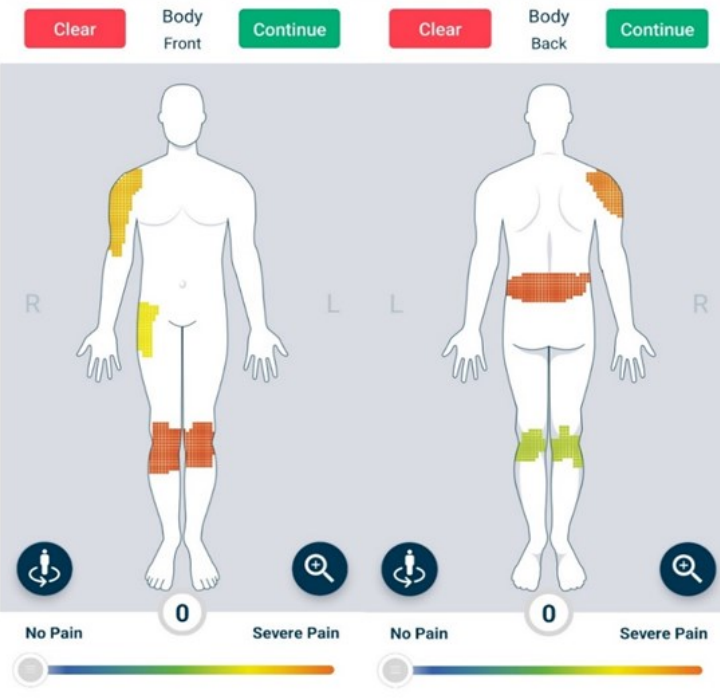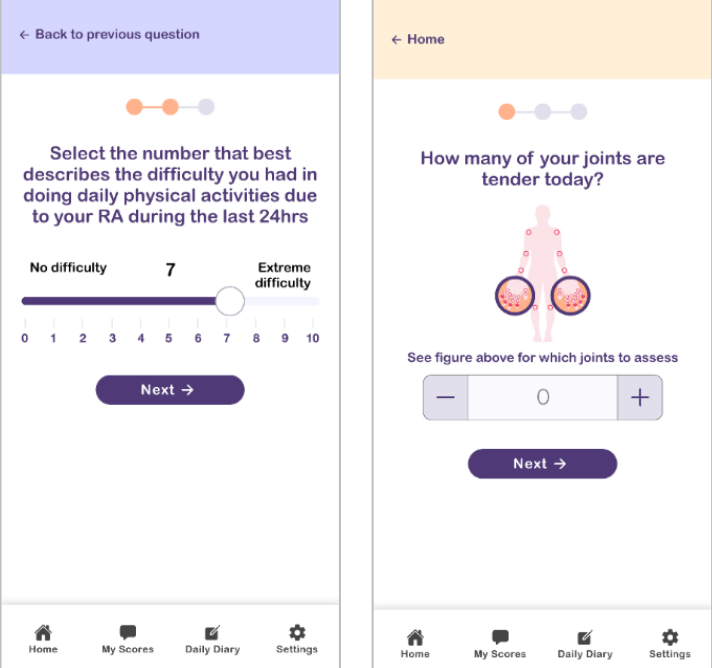
(b) *Remote Monitoring of Rheumatoid Arthritis (REMORA)*, a remote symptom monitoring tool for people with rheumatoid arthritis (**Austin et al., 2020**)

(c) *Keep on Keep up (KOKU)*, an NHS-approved app that helps older adults improve strength, balance and optimise healthy ageing (**Stanmore et al., 2021**)

(d) چین (*Gene*), an evidence-informed app co-designed with the Pakistani community to improve genetic literacy

See **Figure 1** for more details of each. The below recommendations are drawn from the experience of engaging with Pakistanis in patient and public involvement activities as well as research activities to design, develop and evaluate digital health apps mentioned above[i]. However, these recommendations may apply to other South Asian groups (e.g., Bangladeshi, Indian) and other types of health research.

Figure 1: Brief overview of the health apps.
(Images © University of Manchester, included with permission)

| App Name and Brief Description	Screenshots of health apps
Manchester Digital Pain Manikin is a smartphone-based app that enables users to self-report the location and intensity of their pain by drawing on a human-shaped figure with their finger. The pain self-reports drawn from the app can be used to facilitate pain self-management, patient-provider communication about pain and guiding clinical decision making.	
The *Remote Monitoring of Rheumatoid Arthritis (REMORA)* app enables people with rheumatoid arthritis to daily track their symptoms using their own smartphone. Their symptom data is shared with the rheumatology team, who access the data as a graphical summary within the patient's electronic health record. The summary provides a clearer picture of how a person's rheumatoid arthritis has been in between outpatient visits. By discussing the summary as part of the consultation, patients and health care professionals can make better, shared disease management decisions.	

Keep On Keep Up (KOKU)[ii] is an NHS approved, tablet-base app. It is designed to prevent falls, frailty and functional decline. It provides a personalised strength and balance exercises based on evidence-based routines that reduce falls. KOKU also incorporates health literacy games to raise awareness of how to improve bone health, nutrition, hydration and enhance safety in home.	
جین (Gene) is an educational app co-designed with and for the Pakistani community. The app features written information, videos and animations both in English and Urdu, covering topics related to genetic disorders, genetic counselling and consanguinity. The overall aim is to foster genetic literacy and empower the community to make informed decisions about conception, marriage, and support them in accessing genetics services.	
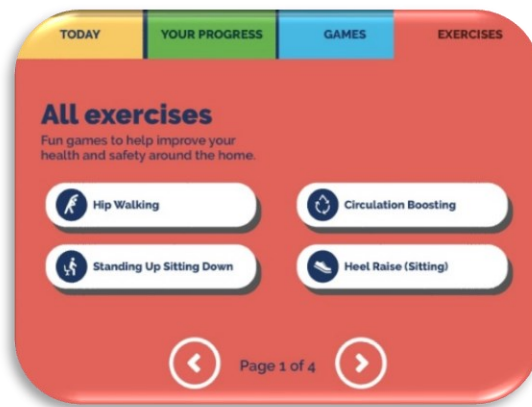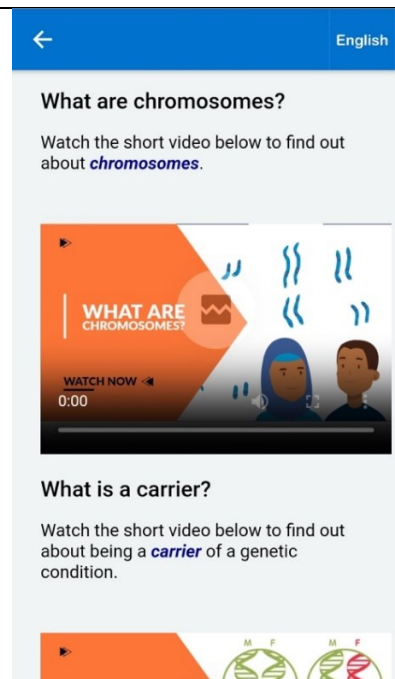
Understanding the relationship between culture and health behaviours

When addressing ethnic health inequities, recognising the difference between ethnicity and culture becomes increasingly important. Though there are similarities across SAs, but specific sub-groups within SA (e.g., Hindu Indians vs Pakistani Muslims) might have distinct cultures (e.g., regarding gender, marriage, social hierarchy and religion), which need to be considered in order to enable successful engagement and research participation that may lead to positive change in health behaviours. Therefore, we need to understand the relationship between culture and health behaviour. We argue that the development and scalability of digital health apps can be synergised by drawing cultural similarities between different ethnic groups living in a country. To draw these similarities, we first need to acknowledge and understand these differences. For example, a Pakistani individual born and raised in the UK may have more cultural similarities with the indigenous population than their parents and grandparents, who were first-generation immigrant to this country.

The influence of culture on health behaviours is not clearly understood, which may lead to research approaches and intervention designs being guided by incorrect assumptions. In addition, marriage and families are culturally important (**Yeung et al., 2018**), which should be acknowledged. For example, for sensitive areas, such as genetic counselling, there is the challenge of engaging both men and women in designing a tool to improve genetic literacy, particularly with men because of their perception about women being solely responsible for genetic anomalies in foetuses or children. However, due to consanguineous marriage practices often recessively inherited genetic anomalies can arise, which are passed on through both the male and female lines (**Merten, 2019; Temaj et al., 2022**). Moreover, it was contested as to what extent religious leaders should be involved in familial decision-making related to consanguinity (close relative marriage) and its implications on genetic disorders, because some participants were supportive of religious leaders' involvement whilst others were more cautious. While consanguinity is not limited to SA populations, there are higher rates of consanguineous marriages within these groups. For example, the UK Born in Bradford study with a cohort of 12,453 women uncovered that rates of consanguinity were significantly higher in Pakistani women, compared to their white British counterparts (37.5% vs. 0.0% for first-cousin marriage) (**Bhopal et al., 2014**). Therefore, it is important to understand existing cultural norms around sensitive areas like genetic counselling and to address them with digital tools and resources, cautiously.

Representativeness and inclusive health research

We need to plan and conduct more inclusive (i.e., people feeling or being able to take part) and more representative (i.e., study sample represents target population) research. In research areas with many unanswered questions around causes of inequities, it may even be appropriate to aim for over-representation of SAs or to conduct studies with SAs only. In turn, this will facilitate researchers in bringing a focus on intersectionality across other characteristics beyond ethnicity. e.g., SA household women of older age from a low socio-economic background with a language barrier. Acknowledging intersectionality, inclusiveness in health research might have different considerations which is why targeting sub-groups (based on specific characteristics) could be a helpful start towards understanding and addressing ethnic health inequities (**Husain et al., 2022**). For example, in the REMORA programme we conducted interviews in Urdu to consider language and other barriers in accessing health services and health apps. This enabled a focus on Urdu speaking people from Pakistani communities in Greater Manchester in order to understand their specific needs and requirements. The intersectional approach will help us unpack the complexities in transitioning from a single disadvantage (e.g., language only) to multiple disadvantages (e.g., language as well as gender, age and employment status) which can be addressed through relevant adaptations in digital tools.

For general population health research, ensuring inclusiveness and diversity is still important for understanding and addressing ethnic health inequities. For example, in our Manchester Digital Pain Manikin research, we conducted a feasibility study with 104 people (**Ali et al., 2023**) and concentrated our efforts on recruiting people from Pakistani background because of Greater Manchester's demographics and pain prevalence statistics. We were able to recruit only six Pakistani participants (i.e., ~5% of the total population of Greater Manchester), which was representative of the total Greater Manchester population but lacked generalisability (i.e., because of statistically limited sample size). Regardless of the inability to draw meaningful conclusions, we benefited from the diverse sample by learning inclusive research practices and recruitment approaches, which would support future health research.

Recruiting SAs with a particular background is more challenging than just recruiting SAs without any consideration. For example, for addressing ethnic health inequities in pain management, researchers should conduct a comprehensive literature search to know which SA sub-groups are contributing more to pain inequities (e.g., SAs from low socio-economic backgrounds), and then try to recruit those people. As there might be some reporting biases in the published literature, researchers may

consider accessing primary data sources or databases to draw this information about the sub-groups with SAs. This way, research will be more inclusive, representative (sometimes over-representative) and likely to create a positive impact.

Approaches to including South Asian communities

Lack of awareness or interest in research studies, lack of information and negative perception about health research, and poor health literacy are the main drivers for the underrepresentation of SAs in health research (**Ali et al., 2023; Kripalani et al., 2021; Sheridan et al., 2020; Vida et al., 2015**). Therefore, as part of a recruitment strategy, researchers should consider raising awareness about how participation in research can be beneficial for the participants themselves and for their wider communities. This can be done by developing and disseminating educational videos and educating local community leaders. This would help the community understand what research means and what research participation entails. Researchers of the same ethnic background and engaging with communities and their local community leaders can also help to build trust between researchers and their future participants (**Ali et al., 2024**).

In addition to a lack of knowledge about research, a lack of trust in digital health technologies and research is also a barrier for Pakistani communities (**Aldosari et al., 2023; Wadhawan et al., 2023**). In terms of recruiting or engaging with Pakistani people, credibility of and relationship with a person are important considerations for approaching these communities and sharing information with them about any health research. For building trust in health research, we recommend leveraging the existing relationship between Pakistani communities and community-based organisations, including mosques (**King et al., 2017; Kokab et al., 2020**), ethnicity-specific charitable and health-related organisations. There are several community-based organisations in Greater Manchester, and we found approaching communities via these organisation or local community leaders an effective strategy for recruitment, involvement and engagement. It is important to note that building trust takes time, so collaborating with people who already work within the community can be extremely helpful.

In addition to building relationships with community-based organisations and community leaders, the role of a diverse research team, including a researcher from the same ethnic/cultural background, is extremely important in approaching and recruiting participants. We found that participants may be more willing to engage in research when researchers look like them and speak their language, as there is a mutual understanding of cultural norms.

As SAs, especially Pakistanis are considered a socially cohesive community, the *snowball sampling technique* can be adopted for approaching potentially eligible study participants, where already recruited study participants can explain research to their peers with potential eligibility and can refer that person to the research team (**Valerio et al., 2016**). Although giving gift vouchers or incentives is a recommended practice for compensating participants for their time spent on data collection, researchers should consider incentivising the person who is spending their time explaining research to others[iii] (**Perez et al., 2013**).

Cultural and linguistic adaptations of health apps and study materials

South Asians are a linguistically diverse community, so developing linguistically competent digital health apps and study materials and resources is challenging. For example, there are Pakistanis, who can only speak or read one language (i.e., English, Urdu, or Punjabi), and there are others who can speak multiple languages but can read only one. Those who can speak Urdu may not necessarily read Urdu, and the same is true for English or Punjabi speaking Pakistanis.

It is also important to recognise that because of poor literacy, particularly health literacy among many Pakistanis, a linguistic adaptation of key health-related terminologies might be challenging. For example, in the Manchester Digital Pain Manikin programme, users should be able to report their pain, of which pain quality (e.g., tingling, numbness) is an important aspect. Since many Pakistanis would not know what 'pain quality' refers to (not even in their native language), they would require additional information to understand and report it within the pain manikin app. Similarly for the Gene, the term DNA does not exist in Urdu, which we explained by describing a helix in animations. Therefore, when appropriate translations of certain terminologies are not available then other methods of cultural adaptations should be considered. In addition to language translations, cultural adaptations were undertaken to increase inclusivity for SAs. For example, in the KOKU app iterative feedback from SA communities informed the adaptation of skin tones for the animated exercise coach and other characters within the app. A range of skin tones were requested by SA study participants to reflect the diversity within the communities. Similarly in the animations for Gene, head scarf, facial features and analogies used in animations were adapted for animations to be more culturally appropriate.

There are many examples of cultural and linguistic adaptations of digital health apps, however, there are fewer examples of cultural and linguistic adaptations of study resources (e.g., study flyer, participant information sheet, consent form) to enable research participation. Language is an important determining factor for enabling research participation,

however, translated materials alone may not warrant their participation unless they have trust in research or digital health apps. In this regard, undertaking patient and public involvement activities are extremely important to inform research methods, materials, and recruitment strategies. Below are a few examples:

Displaying research study posters is a typical approach to promote recruitment in research. These contain basic information about a study, e.g., who we want to recruit, their eligibility criteria, contact details to express interest and (often) a brief sentence at the bottom saying, 'you will be compensated for your time'. Brief information about compensation is allowed, but anything more than that may be considered coercive by ethics committees (**Millum & Garnett, 2019**). However, in the Manchester Digital Pain Manikin programme, when we requested support from local businesses (mainly grocery stores in Manchester) for displaying study posters, all of them asked if study participants would be given any money. It might be because the information given was not sufficient or they did not understand what compensation means. In this regard, patient and public involvement activities might be useful in establishing what acceptable compensation would mean to these communities. As monetary incentives are important, researchers and information governance experts should revisit the existing ethical guidelines and principles on what is considered acceptable terminology around compensation (**Saleh et al., 2020**).

Similarly, the content of a *participant information sheet* and the method of its delivery (e.g., paper format vs video format) should be carefully considered. As a participant information sheet provides all relevant information about a research study and explains procedures that have potential to build participants' trust, researchers should see if it delivers what it intends to deliver. For example, people might have heard key terminologies like pseudoanonymisation, data protection, privacy and confidentiality, but in our experience, we have noticed that SAs often do not fully understand these terminologies. Therefore, researchers should consider translating the content with the use of culturally appropriate terminologies and deliver the content in alternate formats, such as audio, video, and animations.

Conclusion

Widening participation from South Asians in health research may help to address existing ethnic health inequities. However, changing research practices is a prerequisite for ensuring more inclusive research and engaging with South Asians to enable their participation in (digital) health research. Also, the cornerstone of changing research culture should be around approaches to building South Asians' trust in digital health

technologies and research. Planning inclusive research requires deliberate efforts in approaching, recruiting and retaining people with relevant characteristics, which would have huge cost implications. Hence, to support this innovative funding mechanisms should be introduced. Evidence, generated through inclusive research will not only help us understand the underlying mechanisms of ethnic health inequities, and to develop culturally acceptable and accessible digitally enabled interventions, but also to evaluate their efficacy and effectiveness in addressing ethnic health inequities.

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Endnotes

[i] While a numerical expression of involvement and research activities may have been of valuable here, due to the duration over which these activities (over 5-7 years) took place these figures are not readily available.

[ii] Learn more about Koku here: https://kokuhealth.com/.

[iii] The authors have made use of this approach in their own projects and found it most useful. However, the authors are yet to publish this work.