PRIME
Protecting Minority Ethnic Communities Online

TOWARDS ANTI-RACIST INCLUSIVE PRIMARY HEALTH CARE IN THE DIGITAL AGE

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Key findings and policy implications

1 Patient-facing primary health care services have been rapidly digitalised over the past few years, underpinned by digital health and social care strategies in England, Scotland and Wales. Digital services have generated many benefits, for instance, by increasing timely access to healthcare among some individuals and reducing time spent on routine tasks caried out in general practices. However, many individuals from minoritised ethnic communities (also widely referred to as ethnic minorities or minority ethnic communities) face formidable challenges in engaging with processes of digitalisation, particularly older people. At the level of practice, varying levels of support for digitalisation were also expressed.

2 Some of the barriers faced include lack of access to digital resources, and lack of support with engaging with digital services. High rates of poverty in some ethnic groups particularly hinder access to digital primary care. Consequently, non-digital means of communication (such as telephones and in-person visits) need to continue to be available alongside systems and processes of digitalisation as part of an inclusive and integrated healthcare system.

3 Varying levels of support are employed by general practices for minoritised ethnic communities to engage with digital services, for instance through employing bilingual staff in areas where these communities are concentrated. However, increased responsiveness within the NHS is required to support these individuals, alongside the continued availability of non-digital means of accessing and using digital services. Greater recognition of the varying abilities of individuals to read and write English plays a vital role in enabling individuals to engage with digital primary care services. The standard use of English in digital communication without access to language support in many general practices needs to be urgently reviewed to ensure equal access to primary health care and reduce health disparities.

4 Incorporating authentic and meaningful processes of co-design and co-production in digital systems, processes and tools will enhance the affordability, accessibility, appropriateness and linguistic sensitivity of health care to minoritised ethnic communities, and contribute to early diagnosis and treatment. Such processes would also help to cultivate trust in digital services and could be facilitated by collaborating with community organisations.

5 Data collection and management protocols need to incorporate appropriate safeguards to address minoritised ethnic individuals' concerns that information collected through processes of digitalisation, particularly ethnicity data, could be used to discriminate against them, for surveillance or otherwise threaten their safety and privacy, for instance, through data breaches. Privacy-enhancing technologies which are co-designed and evaluated with individuals from minoritised ethnic communities and the organisations which work with them play an important role in addressing such concerns.

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INTRODUCTION

This policy briefing is informed by extensive research – including interviews with minoritised ethnic individuals and interviews with policy-makers and general practice managers – conducted by the UKRI-funded Protecting Minority Ethnic Communities Online (PRIME) project. PRIME is a collaboration between five universities led by Heriot-Watt University. The project has also engaged extensively with individuals with lived experience who acted in an advisory capacity, community organisations, policy actors and other stakeholders throughout the research process. Launched in April 2022, PRIME has identified the distinctive online harms minoritised ethnic communities face amidst the rapid digitalisation of primary healthcare, social housing and energy, and developed innovative and groundbreaking social and technical tools to empower policymakers, practitioners and regulators to create safer, more equitable online spaces. The focus of this briefing is on primary health care.

POLICY AND LEGISLATIVE CONTEXT: THE DIGITALISATION OF THE NHS AND PRIMARY HEALTH CARE

The UK Government's ambitious vision of digital transformation was articulated in the updated *UK Digital Strategy* in 2022 (2). This strategy set out the government's plan to build robust digital infrastructure and a secure digital environment across the nations. Scotland and Wales have devolved governance administrations which allow them to develop their distinctive national digital strategies in addition to the *UK Digital Strategy*. In Scotland, this has been recently updated as: *A changing nation: how Scotland will thrive in a digital world in Scotland* (3) while the Welsh government has recently updated its *Digital Strategy* (4).

Successive governments have emphasised the importance of digitalising the NHS, highlighting the potential for improved personal risk management, treatment and care (5, 6). In England and Scotland, practices are encouraged to adopt a 'digital first' but hybrid approach, integrating online access with non-digital channels like telephone and in-person visits (7, 8). England's digitalisation strategies are detailed in the *2019 NHS long term plan* aiming to ensure every patient has digital access to primary care by 2023/24 (7). In Scotland, where health services are devolved, the *NHS Digital Health and Care Strategy* was published in 2021, with a rolling three-year Delivery Plan adopted in 2022 (8). More recently, in 2024, Digital Health and Care Wales launched the first Welsh long-term

Organisational Strategy 2024–2030 as well as the Primary Care Strategy 2024–2027 to drive and expand digital transformation in Welsh health care services (9, 10).

However, these visionary plans need to be considered in the light of existing racialised inequalities in primary care services, in order to ensure that these are not replicated or exacerbated, or that new inequalities do not arise. Here, it is worth underscoring the Public Sector Equality Duty set out in the Section 149 of the Equality Act 2010, which applies to GP practices including private practices delivering NHS services (in respect of those services), as well as commissioning bodies. This duty places a responsibility on general practices, along with other public bodies, 'to eliminate unlawful discrimination; advance equality of opportunity between people who share a protected characteristic and those who don't and to foster or encourage good relations between people who share a protected characteristic and those who don't.' The Equality and Human Rights Commission has produced guidance for public sector organisations on how to consider equality in policy making in England (11).

NOTE ON TERMINOLOGY

In this briefing, the term 'minoritised ethnic' refers to non-White ethnic groups in the UK who are categorised by the UK and Scotland's Census as Black African, Black Caribbean, Bangladeshi, Indian, Chinese, Pakistani, and Mixed or Multiple ethnic heritage. The self-identified ethnicities of these groups are, however, often significantly more complex. Minoritised ethnic individuals are also widely referred to as 'ethnic minorities' or 'minority ethnic communities', terms which compare certain ethnic groups against the majority population in numerical terms. This document employs the term 'minoritised' rather than 'minority' to highlight that these communities are subject to processes of marginalisation and exclusion due to their ethnicity—encompassing culture, language, religion, and observable features such as skin colour (1).
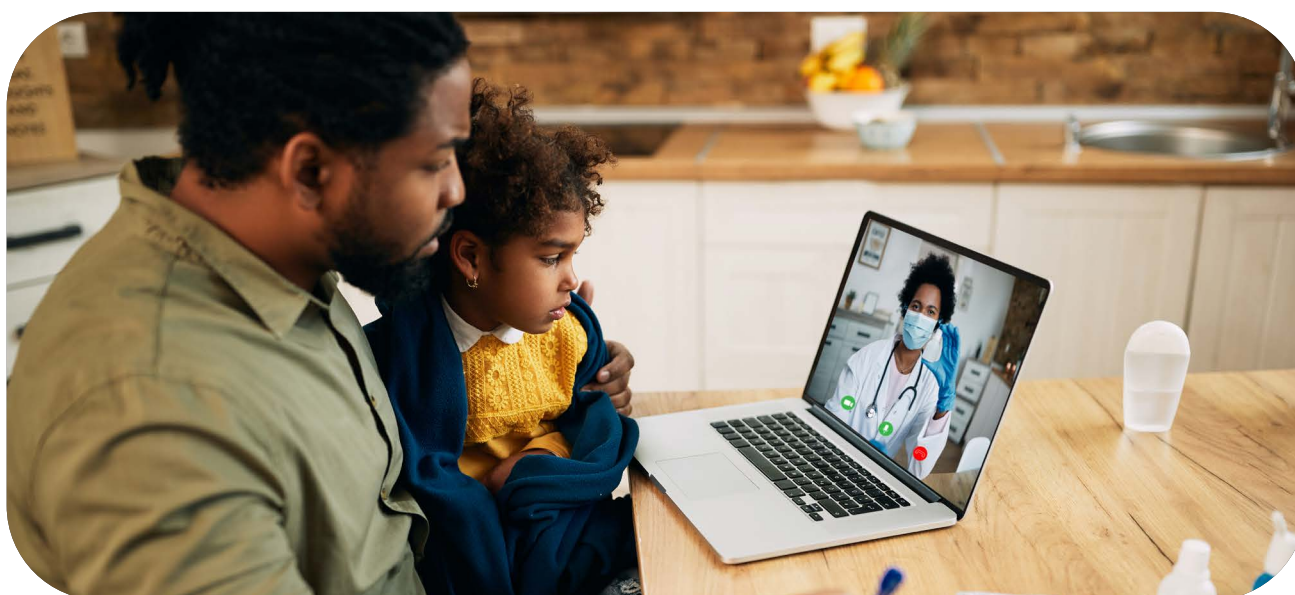
EXISTING RACIALISED INEQUALITIES IN PRIMARY HEALTH CARE SERVICES

Inequalities in primary health care for minoritised ethnic communities in the UK are persistent, characterised by disparities in access, quality of care, and health outcomes (12). Individuals from these communities have repeatedly reported lower satisfaction with primary care services (13, 14). Inequalities stem from, among other things, inadequate language support, cultural incompetencies, and experiences of racial discrimination. Language barriers, for instance, hinder patient access, care continuity, and the patient journey, with inadequate interpreting support available for those with limited language proficiency (15–17). Additionally, a lack of culturally competent healthcare professionals (18, 19), restricts access to appropriate primary care (20, 21). Implicit biases among healthcare providers can lead to differential treatment, where minoritised ethnic patients' symptoms are taken less seriously, resulting in delayed diagnoses and inadequate treatment. For example, Black men are less likely to receive timely dementia diagnoses (21), and minoritised ethnic patients often experience delays in referrals to secondary care, such as having to visit their GP more times than their White counterparts before receiving specialised care (12, 16). Structural racism and institutional biases further exacerbate these inequalities (22).

In the remainder of this briefing, drawing on empirical research conducted in England and Scotland, we consider current practices in the delivery of 'digital first' primary health care; digital resource and language support barriers among minoritised ethnic communities; and concerns around data collection and use, underscoring the urgent need to safeguard patients' safety and privacy, as well as the potential for data to be used more proactively to improve access to early intervention and treatment through targeted approaches.

1 CURRENT PRACTICES IN THE DELIVERY OF 'DIGITAL FIRST' PRIMARY HEALTHCARE

This section analyses the implementation of digital-first approaches, considering their implications for minoritised ethnic patients, the effects on general practices, and the challenges practices face. Digital-first approaches are predominantly characterised by a top-down implementation strategy, in which general practices play a critical role in integrating and delivering digital technologies for patient care. However, general practice managers have highlighted that financial constraints and contractual arrangements significantly influence the adoption of specific digital tools, such as apps with integrated language support. Moreover, there are substantial variations among practices regarding digital readiness, infrastructure, staff competencies, and the patient-facing apps employed. While general practices are encouraged to maintain access to non-digital channels, our research with individuals from minoritised ethnic communities revealed that many patients experience considerable pressure to access primary health care digitally, with some even being informed that non-digital channels are no longer available.

According to general practice managers and minoritised ethnic individuals, particularly in England, patients are often expected to use 'online consultation forms' via web or mobile applications to check and communicate symptoms, upload photographs of symptoms, book appointments, and order repeat prescriptions. In general practices, online consultation forms are anticipated to reduce practice costs and staff workloads by minimising the need for telephone interactions. However, this was tempered by recognition that some digital processes pose challenges for minoritised ethnic individuals, particularly in relation to lack of language support. Among minoritised ethnic individuals, concern was also highlighted that the routine use of photographs may result in erroneous diagnoses and delayed treatment for those with darker skin.

Some support was articulated among practice managers for co-designing apps with minoritised ethnic communities and promoting collaboration among stakeholders and healthcare providers to ensure more accessible digital services. More fundamentally, strategies to address inequalities in digital primary care require authentic and meaningful co-production in organisational systems and processes (23, 24) as well as consideration of existing research, and policy and practice recommendations (14). The Minoritised Ethnic People's Code of Practice for Equitable Digital Services contains principles and recommendations to guide the development of digital services. Underpinned by seven principles – fairness, compassion, user-centred, accessible, transparent, private and secure, and trustworthy – it offers a guide for decision-making about the purpose, design, delivery and use of personal data, to help safeguard against the inequities experienced by individuals in this section of the population in access, experiences and outcomes of these services.

2 DIGITAL RESOURCE BARRIERS

Interviews with minoritised ethnic individuals, many of whom are first or second-generation migrants, revealed that they face significant barriers to accessing primary health care through digital services. These barriers stem from a lack of access to digital resources, which include sufficient and reliable internet data, digital devices of adequate quality, and digital skills.

Many older first-generation migrants, especially women, either lack access to smartphones or only have the skills to use them for spoken communication. Further, individuals on low incomes across all age groups and migration backgrounds struggled with the affordability of digital primary care, which requires ownership of, or access to, a digital device with sufficient memory to download GP apps and reliable internet connectivity. Among those with access to digital devices, smartphones were the most commonly used device. However, the smartphones which some minoritised ethnic individuals had access to were often of inadequate quality. This issue is exacerbated by frequent updates to GP apps and the need to use multiple apps simultaneously for various services, such as booking appointments and requesting medication. Updating existing and installing new apps consumes memory, leaving some individuals with inadequate storage space. Digital exclusion is particularly acute for individuals living in insecure housing, who are often unable to sign up to broadband contracts and hence must rely on limited mobile data for all their internet needs.

While the affordability of digital devices and internet connectivity affects socio-economically deprived individuals across all ethnic groups, some minoritised ethnic communities are disproportionately disadvantaged due to their higher levels of socio-economic deprivation (25).

Varying levels of digital skills also impede access to digital healthcare. Even individuals who consider themselves digitally proficient encounter difficulties when required to perform complex tasks, such as uploading photographs to specific portals or completing online forms. These challenges are particularly pronounced for older and mid-aged adults. While individuals across all ethnic groups experience digital literacy challenges, these challenges are exacerbated for minoritised ethnic individuals due to disparities in educational and employment opportunities, which are positively correlated with digital skills acquisition (26, 27). Although some individuals with limited digital skills, including older adults, have previously received digital skills training, they nonetheless struggle to use digital apps, partly due to the continually evolving nature of digital healthcare technology.

Practice managers acknowledge that limited digital skills among the older population presents substantial challenges in engaging with digital apps. However, practices vary in terms of how responsive they have been to such challenges. Some practices have retained

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alternative communication methods to reach older patients. In practices where non-digital channels have been phased out, practice managers reported introducing iPads and tablets in waiting areas to assist patients in accessing services. However, this measure may be insufficient to support excluded individuals particularly when they are unwell and need to communicate with their general practice from home. The obstacles emerging from lack of access to adequate digital devices and limited digital skills are further compounded in the case of minoritised ethnic individuals by lack of language support, an issue to which we now turn.
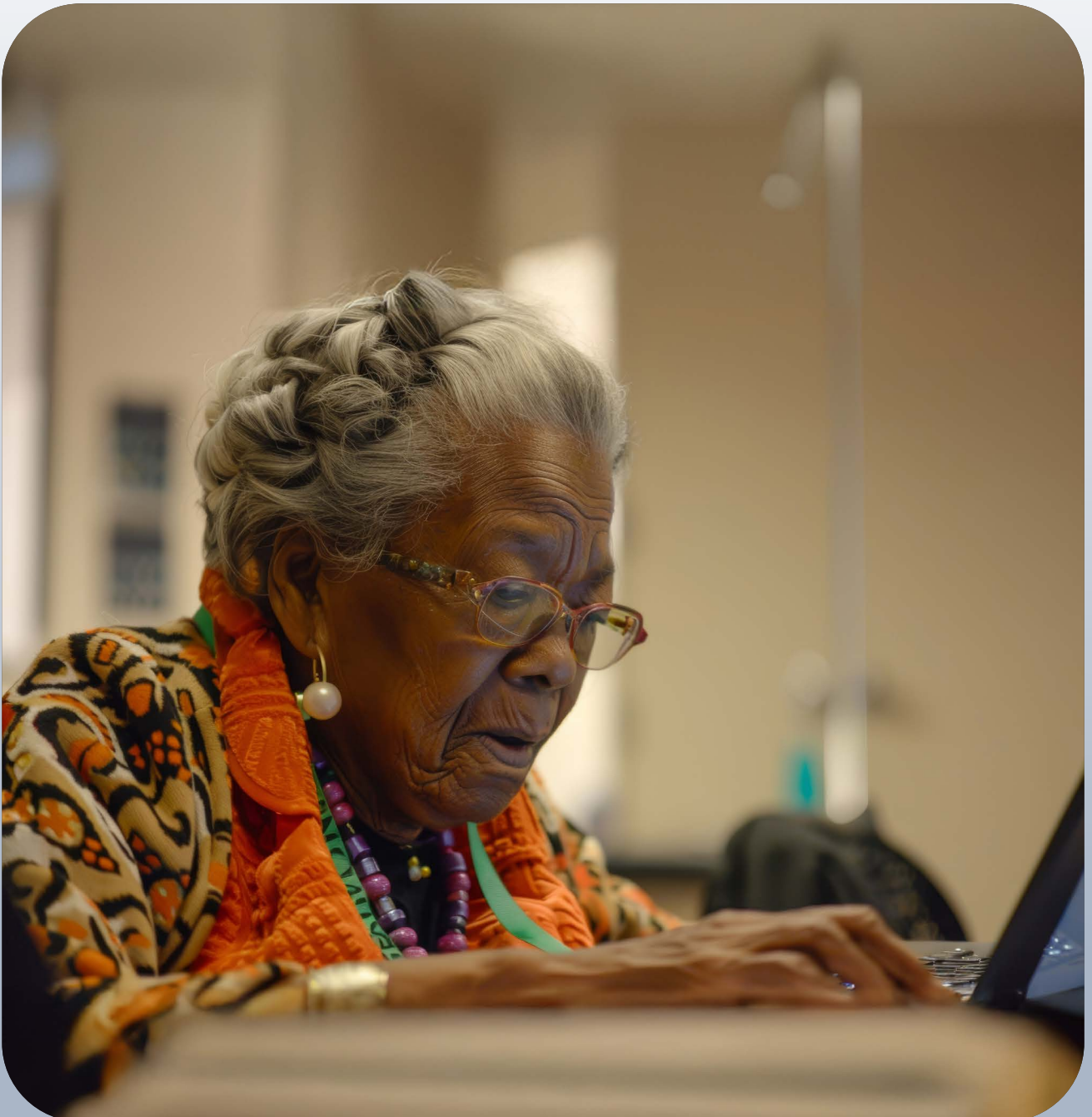
3 LANGUAGE SUPPORT BARRIERS

As indicated earlier, the lack of language support in primary health care services has been extensively documented prior to the shift to digitalisation (16, 17). Digitalisation further impedes access to appropriate language support for minoritised ethnic patients. Most GP platforms and apps are only available in English. Further, unlike non-digital primary care services, digital primary care requires patients to communicate complex information in written English. For instance, securing a GP appointment frequently involves describing symptoms and sometimes requires providing a detailed medical history via online consultation forms. This presents a challenge for older first-generation migrants in particular who may have some proficiency in spoken but not written English. The routine use of text-heavy platforms further exacerbates access difficulties for individuals with limited proficiency in written English.

Obtaining interpreting support from GPs to complete online consultation forms or participate in online consultations is extremely challenging, leading most non-proficient English speakers to rely on informal assistance, particularly from family and friends. While some language support is available at GP practices through bilingual staff, these resources are not always available when needed. Moreover, relying on family members for language assistance often compromises the privacy of patients. The gradual elimination of non-digital access options has, nonetheless, forced many to rely on family members for accessing healthcare digitally. Where this is not available, individuals have reported resorting to home remedies, or even foregoing seeking care altogether.

The shift to digitalisation also increases the burden placed on informal carers within the family, who tend to be mid-aged women, who are in some cases, also managing digital healthcare accounts for their minor children. This added responsibility sometimes results in mid-aged women delaying seeking treatment for themselves, complicating access to primary health care.

Interviews with practice managers revealed that financial constraints limit their capacity to extend support for patients with language barriers in accessing digital healthcare. They have also had to change digital tools in a short timeframe, which also hinders some practices from using apps with translation functions. Such limitations highlight the need for greater attention to this area to avoid widening existing disparities in access to primary health care.

4 TRUST, PRIVACY AND DATA SECURITY

NHS England's statutory guidance (28) emphasised the need to build trust among minoritised ethnic communities. However, our interviews revealed persistent feelings of mistrust and fears of discrimination among these communities in their use of digital health apps including in relation to handling ethnicity and other sensitive data. Some interviewees even expressed concerns about increased data collection leading to heightened state surveillance. Interviews with minoritised ethnic individuals further highlighted that those living in close-knit communities are particularly apprehensive about data management, often due to prior experiences of data leakages from their practices.

There are numerous challenges associated with data collection, including some minoritised ethnic individuals' reluctance to disclose their ethnic identity or immigration status to healthcare providers. Practice managers and health professionals revealed that withholding ethnicity information undermines the quality and consistency of ethnicity coding within NHS institutions. Such shortcomings not only hamper efforts to document and address racialised health inequalities but also limits the understanding of digital healthcare usage patterns across different ethnic groups—an understanding essential for designing equitable and inclusive healthcare initiatives.

Further, practice managers indicate that online data collection systems are never entirely risk-free in the context of technology-based record-keeping. As healthcare information becomes more digitalised, the risk of data breaches and leaks rises, posing long-lasting and potentially irreversible consequences due to the permanent nature of digital records. Additionally, concerns about third-party access to patient medical records and the risk of cyber-attacks underscore the urgent need for secure and robust data management protocols within NHS settings.

This issue is further compounded by a lack of transparency from practices regarding data use, including the reasons for collecting data and with whom it is shared. This lack of communication is particularly concerning given the importance of collecting ethnicity data for the early detection of diseases and the development of targeted interventions for specific ethnic groups at higher risk for certain conditions, such as prostate cancer among men of African heritage. Despite these benefits, the absence of clear explanations and reassurances from healthcare providers has exacerbated mistrust.

To address these challenges, there is a pressing need to consider how general practices should gather and analyse information about equality and to develop and adopt a reliable, patient-informed, secure data integrity protocol. Guidance relating to the collection and analysis of equality data in England has been produced by Equality and Human Rights Commission (11). This protocol must prioritise the protection of patient privacy, including the sensitive handling of ethnicity data, to ensure accountability at all levels of data collection, recording, and sharing within NHS institutions. By safeguarding patient privacy with the utmost priority and developing effective communication strategies on data collection and use, healthcare providers can foster a more trustworthy relationship with minoritised ethnic communities, ultimately enhancing their engagement with digital healthcare services. Privacy-enhancing technologies which are sensitive to the concerns of minoritised ethnic patients can also play a valuable role in increasing trust and confidence in this area.

CONCLUSIONS

In summary, our findings highlight significant barriers to primary health care access and use. These challenges are related to limited access to digital resources, insufficient language support, and concerns around data collection and usage. For patients, such obstacles often lead to anxiety, distress, and delays in receiving care and hinder engagement with primary care. Our findings underscore the urgent need for an ethnicity-inclusive digital healthcare framework within general practices. This framework must protect non-digital access channels, ensuring that excluded groups can still obtain primary health care. It should also include robust guidelines for developing ethnicity-inclusive apps which incorporate language support, while addressing data privacy concerns in primary health care. By tackling these issues, we can build a more equitable and anti-racist healthcare system that truly serves all communities.

METHODOLOGICAL NOTE

This research draws on multiple primary data sources: 100 narrative interviews with minoritised ethnic individuals, supplemented by 15 follow-up audio-visual interviews; 12 interviews with general practice managers; 6 interviews with senior officials from key national organisations, including NHS England and the Scottish Government; a workshop involving health policymakers; and desk-based review of Governments' digital health and social care plans and strategies in England, Scotland and Wales. Minoritised ethnic interviewees were purposively recruited from four case study sites—the London Borough of Tower Hamlets, Bradford, Manchester, and Glasgow—to explore their lived experiences of GP services in the digital era. To ensure the participation of minoritised ethnic individuals with language barriers, language support was provided during the interviews. Discussions with general practice managers and senior officials focused on the drawbacks and challenges of ensuring equitable access for minoritised ethnic communities to digital primary health care. The workshop with policymakers provided a collaborative platform for stakeholders to exchange ideas and experiences, aiming to capture practical perspectives on addressing ethnicity-related inequalities in the transition to digital primary care. All interviews and workshop notes were thematically analysed to reveal how ethnicity intersects with other characteristics (e.g., age, gender, language, socio-economic status) to facilitate or hinder minoritised ethnic communities' access to and engagement with digital healthcare channels.

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FOR MORE INFORMATION

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