UNIVERSITY OF OXFORD

NHS RACE & HEALTH OBSERVATORY

Patient Experience and Trust in NHS Primary Care

Lay Summary

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The survey was designed and disseminated by the NHS Race and Health Observatory. The data analyses and main report writing were undertaken by Dr. Joanna Demaree-Cotton and Prof. Ilina Singh from the University of Oxford. The summary report was written by Alexander Pearn and overseen by Dr Ngozi Kalu from the NHS Race and Health Observatory.

Introduction

Trust is foundational for effective primary care and is an essential factor in shaping the relationships between healthcare providers and their patients. So much so, that it is a fundamental pillar in ensuring individuals engage with healthcare services, adhere to treatments, and achieve positive health outcomes. However, for many ethnic minority groups in the UK, this trust has been eroded. This report analyses the resulting disparities and challenges faced by ethnic minority communities, and provides actionable recommendations for improving the systematic issues identified.

These disparities are nothing new and have been well-documented for decades with research consistently showing that ethnic minority groups in the UK experience worse health outcomes compared to White British groups. For example, Bangladeshi, Pakistani, and White Gypsy or Irish Traveller communities exhibit the poorest health outcomes, while rates of infant and maternal mortality, cardiovascular disease, and diabetes are higher amongst Black and South Asian groups. These pre-existing inequities were starkly exposed in 2020, when the COVID-19 pandemic saw ethnic minority communities experience higher rates in both mortality and disruptions in access to care. Urgent and direct attention is needed to unpack and address these inequalities.

Trust between patients and healthcare providers is fundamental when seeking care, as it touches upon both physical and emotional vulnerability when disclosing personal information and following medical advice. Trust consists of two key components: practical and epistemic. Practical trust refers to a patient's confidence in a healthcare professionals' competence and good intentions, while epistemic trust is a belief in the honesty and reliability of the medical information given. Should either area begin to breakdown, patient disengagement will quickly follow and so too will worsening health outcomes. Restoring trust is dual faceted, and rebuilding it requires a careful assessment of systemic issues.

Survey

To understand these healthcare disparities, we ran a comprehensive patient survey, gathering insights from 2,682 participants about their experiences with, and trust, in primary care. The survey looked at aspects of patient experience, particularly focusing on communication, confidence, and instances of discrimination.

The questions were designed to gather information on a range of issues relating to primary care, including:

- Overall trust in, and satisfaction with, primary care providers
- Trust in primary care as an accurate source of information, particularly about Covid-19
- Experiences of provider communication and engagement during consultations.
- Level of satisfaction with remote healthcare services.
- Issues of discrimination relating to ethnicity, language, or other personal characteristics.

The survey also included open-ended questions and encouraged participants to share both negative and positive experiences they had with primary care providers. Survey responses were collected through a combination of online platforms, community networks, and social media. Whilst this approach enabled a broad reach, it could have contributed to a bias in tech-savvy respondents. Yet, the survey achieved meaningful demographic diversity across age groups, genders, and ethnic backgrounds.
The combination of qualitative and qualitative metrics allowed us to identify patterns and trends, whilst also capturing nuance and individuality through all experiences.

Key Findings

The results of the survey provide us with a complex picture of the state of primary care but, ultimately, they reveal just how strained the system is. One respondent (Female, Mixed Other ethnicity, 25-34 years) described how their concerns were dismissed as lifestyle-related without any clinical investigation. It is through accounts like these that the emotional toll of inadequate care can begin to be seen, and the resulting breakdown of trust understood.

Trust Levels

- Practical trust levels were markedly lower in Bangladeshi and Pakistani communities. Key factors influencing trust included feeling listened to, having concerns acted upon, and confidence in remote consultations
- Lack of continuity within care was a common theme. Many participants expressed a desire to build long-term relationships with consistent providers which is key for establishing trust. This is especially important for those managing chronic conditions, with consistent providers being better positioned to understand a patient's history and needs
- Trust in the in honesty and reliability of healthcare advice around Covid-19 was lower in several ethnic minority groups when compared to White British groups, particularly Black groups, Asian groups (except for Indian), and non-British White participants.

Disparities in Patient Experience

- Patients from Bangladeshi, Pakistani, Non-British White, and Black communities report significantly poorer experiences in primary care compared to White British patients
- These ethnic minority groups were all more likely to feel like they aren't listened to by healthcare providers, and 31% of Bangladeshi and Pakistani participants felt that, even when they do access primary care, healthcare professionals do not act on their concerns
- Communication issues, including feeling that healthcare professionals either do not listen or take their concerns seriously, were frequently cited as barriers to trust
- Many participants shared experiences of feeling overlooked and devalued by healthcare providers. They described a lack of empathy for their concerns, rushed consultations and impersonal interactions that lacked genuine care

Impact of Discrimination

- Nearly 49% of survey respondents reported experiencing discrimination from their primary care providers based on personal characteristics, with 25% feeling they were treated differently due to their ethnicity. Among Black Caribbean and Black Other participants, over 50% reported discrimination due to ethnicity

- Discrimination and poorer engagement were found to be closely linked. Ethnic minority participants shared that they were less likely to seek treatment due to past experiences of discrimination. They also highlighted subtle forms of bias, such as being patronised or having their symptoms dismissed, which further added to feelings of exclusion

- Experiences of discrimination were often exacerbated by other intersecting factors, such as gender and socioeconomic status, which further limited access to equitable care

Barriers to Access

- Structural inequities, such as lack of access to preventative care and inconsistencies with follow-ups left patients feeling unsupported and with issues left unresolved

- Many reported challenges when navigating digital health platforms or apps, with many describing difficulties in booking appointments or understanding automated systems, particularly when materials were not provided in multiple languages

- Language barriers, access to interpreters, limited appointment availability, and perceived discrimination were cited as major obstacles to treatment.

Recommendations

1. Integrated Care Systems should work with local communities to improve levels of trust in accessing primary care services in local communities, with a focus on areas where data indicate challenges, e.g. vaccination uptake. (NHS England and Integrated Care Systems)

2. Raise awareness amongst healthcare professionals about racial and ethnic disparities in patient experience of primary care, and its impact on health outcomes including through existing resources and interventions where these exist. (NHS England, Royal College of General Practitioners, Royal College of Nursing)

3. Independently led and co-produced practical guidance for healthcare professionals, including those within primary care settings, on undertaking sustained and effective engagement with ethnic minority communities. (In conjunction with NHS England)

4. Continue investment in cultural competency and cultural safety training and development for primary care professionals, both within healthcare educational curriculum and within professional developmental courses. Including building on existing programs and interventions to enhance inclusivity, accessibility, and representation across the curriculum. (NHS England, Royal College of General Practitioners)

5. Disseminating guidelines and resources that address structural barriers in accessing primary care services, such as access to interpreters and translated materials, longer appointments for non-English speaking patients with interpreters, and improved digital access and enablement. (NHS England)

6. Development and implementation of practical tools to increase culturally appropriate communication on perinatal health in primary care settings. (NHS England to lead and the Royal Colleges to support)

7. Development of a framework to assess, evaluate and hold healthcare providers accountable for addressing ethnic health disparities, such as trust metrics, patient feedback loops, and transparency within performance metrics. (Care Quality Commission, NHS England)

8. Improve the quality of ethnicity coding for patients in primary care, including:

    a. Ensuring the latest guidance is being implemented
    b. Routinely monitoring the quality of ethnicity coding
    c. Continuously identifying how ethnicity coding can be improved and putting in place actions to achieve this. (NHS England)

9. Further research on the development of evidence-based strategies to improve trust between ethnic minority communities and the healthcare system. (National Institute for Health and Care Research)

Conclusion

There is a clear need to improve access and experience of primary care for ethnic minority communities. It's also evident that trust has a powerful impact upon not only an individual's healthcare outcomes, but for communities as a whole. Yet, despite how vital a component trust is within healthcare, it has been left to fracture. It's paramount that targeted systemic reforms are implemented to regain trust, enhance cultural competency and create meaningful community engagement.

Through the implementation of the recommendations outlined in this report, healthcare providers can begin to move towards equity in access and health outcomes. Restoring confidence in the healthcare system can lead to life changing benefits to communities that are often marginalised, and will require continued collaboration between policymakers, healthcare providers, and the communities themselves. Only then can the healthcare system truly serve all members of society with the dignity, respect, and quality of care they deserve. The path to equity demands not just acknowledgment of these issues, but active commitment to change at every level of healthcare delivery.

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