

Summary Report: Digital apps and reducing ethnic health inequalities

Driving progress through digital, design,
and organisational transformation.

Recommendations for national NHS leadership including organisations such as NHS Blood and Transplant, NHS England, and NHS Digital, and beyond.

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Executive summary

This review into the relationship between digital and ethnic health inequalities has revealed inequality as a complex, legacy driven, and institutional phenomenon. Reducing health inequalities involves engaging with the systemic structures that maintain the existence of those inequalities. Health inequalities have been shaped by the country's political history, immigration, and wider determinants of health, such as education, employment, and housing; as well as the NHS's complex structure, which collectively contribute to profound ethnic inequalities in health outcomes. Ethnic inequalities can have severe consequences for a person's physical and mental health. Shared across communities and passed down from generations, individual tolls over time become collective trauma. As there are many factors that contribute to inequalities outside health and outside the NHS, we found it impossible, but also reductive, to suggest isolated digital responses to this systemic problem - especially as digital alone cannot address systemic inequality. Even so, the NHS has an important role to play in reducing ethnic health inequalities, with the pandemic revealing that more effort is needed.

Addressing ethnic health inequality requires a comprehensive and systemic NHS response, of which digital can be one powerful driving force.

While there is growing public awareness of racism and ethnic discrimination issues across government, policing, and healthcare, receiving healthcare is a very individual and often isolated experience. Black, Asian, and minority ethnic community members often do not know whether they are receiving an equal quality of care. Only with quality quantitative data can the NHS understand the extent of the problem, and where and how it can shape interventions. **A reform in how the NHS and NHSBT collects and uses data to guide decisions, especially with ethnicity coding, is needed to achieve better health outcomes for all.**

While some of the recommendations made in this report can be implemented by delivery teams today, many of the required actions sit outside the existing remit of the NHS and NHSBT App teams. As such, our report focuses on setting out challenges for national NHS leadership, including organisations such as NHSBT, NHSE, and NHSD. **We argue that digital and app teams need to have an explicit remit to work towards dismantling inequality, by firstly helping to rebuild and strengthen community trust through equitable approaches.** Recent successes including the NHS' new inclusive content design guidelines¹, projects such as A.T. Beacon Community Hubs,² and NHSBT Community Investment Scheme,³ demonstrate how organisations can deliver and scale equitable approaches. **Recognising the value that digital services have already delivered, and can potentially still deliver, for public health, we call for continued NHS investment and commitment in this area to get it right.**

¹ Inclusive content - - - Ethnicity, religion and nationality. NHS digital service manual. "<https://service-manual.nhs.uk/content/inclusive-content/ethnicity-religion-and-nationality>"

² AT Beacon Project. "What We Do." AT Beacon Project, <https://www.atbeaconproject.org/what-we-do>. Accessed 1 July 2022.

³ NHSBT. "Community Investment Scheme report." NHS Blood and Transplant, 2020, <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/community-investment-scheme/community-investment-scheme-report/>. Accessed 1 July 2022

Key messages

1. **Ethnic health inequality is deep rooted, pervasive, and systemic;** there isn't a quick fix to inequality. COVID-19 has accelerated ethnic health inequality while also driving increased uptake of digital tools and remote care. However, the lack of data linking clinical outcomes, demographics, and digital behaviours across the NHS and NHSBT is one of the biggest barriers preventing leaders from prioritising interventions and holding themselves accountable for addressing inequality through digital services.
2. Digital has the potential to help the NHS reach out to a wider group of people, increasing reach, and efficiency, and lowering operational costs. For many people, digital channels are the first points of interaction with the NHS' clinical support. Digital forms a direct interface between patients and the NHS (and related organisations) and has the potential to empower patients and enhance user experience. However, unless carefully implemented, Digital also has the potential to absorb and intensify structural bias and inequality, furthering exclusion for some. National NHS leadership should actively seek to **design health services that intentionally reduce health inequalities, with a clear role and remit for Digital teams.**
3. There is a **lack of access to data and often also the resources and capacity to analyse where ethnic health inequality exists.** This restricts the app teams' ability to work towards reducing this in a targeted way. For the NHS App team, demographic and healthcare data collected and recorded in general practice systems are inaccessible, due to strict controls over how data is used and shared⁴. Though NHSBT collects personal data through pulse surveys, the Give Blood app team currently lacks the data infrastructure, setup, and capacity to rapidly and routinely analyse data for action. Going forward, it is important that the NHS leadership invests in establishing the right processes, training, and cultural change internally around data to build compliance, accountability, and trust.
4. When it comes to expanding and improving how data is collected and shared within the NHS, experts and civil society are concerned about the NHS' track record on data security⁵. From a community perspective, our research found that **people were open to sharing personal data with the NHS as long as it led to tangible health benefits for themselves and their communities, and if clear boundaries were established around how data would be used, protected, and shared onwards.** It is important that as part of designing new data strategies, the NHS engages with the public upfront, and particularly with members of Black and minority ethnic communities, to co-design data policy around community needs. With data needs and expectations always evolving, this needs to be a continuous workstream that informs NHS's wider data strategy.
5. **Dismantling ethnic health inequalities requires systemic interventions that are often beyond the remit of apps alone.** Today, teams delivering healthcare apps like the NHSBT Give Blood app and the NHS App are predominantly digitalising existing services and do not have a clear remit to tackle systemic and legacy issues. We recommend that in the future, Digital be used as a strategic tool to tackle health inequality and racism, as part of a wider organisational commitment. Digital should be one component of designing equitable, inclusive health services - this requires an integrated way of working across the NHS.

⁴ The Personal Demographics Service is the national electronic database of the NHS, including patient details such as name, address, date of birth, and NHS Number, which includes demographic information. Ethnicity data is predominantly captured within GP systems, though it can also be captured as part of the record generated in episodic care across a range of settings and providers. However, this is not mandatory and there are challenges with data quality and completion. The NHS has strict controls over how it uses and shares this person-identifiable sensitive data. More information: <https://digital.nhs.uk/data-and-information/areas-of-interest/ethnicity> and <https://digital.nhs.uk/data-and-information/areas-of-interest/ethnicity>

⁵ Peek, Niels. "We need to re-think health data sharing and public trust, says publication." The University of Manchester, 28 January 2020, <https://www.manchester.ac.uk/discover/news/we-need-to-re-think-health-data-sharing-and-public-trust-says-pub/>. Accessed 1 July 2022.

Key recommendations for a future generation of apps

To make digital and apps a positive force to reduce ethnic inequalities, the teams developing the next generation of apps need a clear remit and the right support to create the conditions for success. This might include dedicated resources to systematically test and implement joined-up interventions, or strengthen trust and relationships with Black and minority ethnic communities.

Drawing on the lessons learnt from the experiences of NHS Digital and NHSBT, we have identified recommendations for a future generation of healthcare apps to better work towards racial equity in healthcare. We have identified recommendations in three areas:

- **Design**
- **Data**
- **Ways of working**

The recommendations have been grouped into three categories based on the implementation approach:

- **Discrete:** Recommendations that digital and app delivery teams could adopt by themselves.
- **Connected:** Recommendations that digital and app teams need to collaboratively work with others towards.
- **Systemic:** Recommendations that require a clear leadership mandate for systemic reform.

Design recommendations

The design and research effort for healthcare apps needs to explicitly be geared towards working with Black and minority ethnic communities to shape and deliver more equitable services.

Discrete

Recommendations that digital and app delivery teams could adopt:

1. Review well known frameworks such as the NHS design principles that often underpin the design and development of NHS, NHSBT and other healthcare apps, to refocus what future best practice looks like for teams actively working to address systemic inequalities.
2. Target design research to identify barriers preventing ethnic minority communities from benefiting from current apps, ideating new solutions that would help mitigate the potential negative impacts of digitalisation.

Connected

Recommendations that digital and app teams need to collaboratively work with others towards:

1. Digital teams should work closely with local NHS GP practices and commissioning groups, frontline staff, and community partners to identify new ways to serve the unique and unmet needs of minority ethnic communities.

New apps or digital services could have new purposes/remits that address challenges and gaps we saw for minority ethnic communities, for example:

- How might healthcare apps empower use by community groups and families, instead of focussing on individual users?
- How might healthcare apps provide trusted and personalised content?
- How might healthcare apps strengthen and improve a GP's relationship with patients?
- How might healthcare apps be accessed and used by diverse, non-native English speakers?

Systemic

Recommendations that require a clear leadership mandate for systemic reform:

1. With better linked data, NHSE, UKHSA, ICSs, researchers and digital teams should use data to design by targeting research and design efforts on areas where ethnic health disparities need most attention. This will also identify additional benefits and purposes for digital tools.

Data recommendations

Digital and App teams need to have linked data cutting across demographics, clinical outcomes, and digital behaviours to actively shape and deliver impactful services that reduce health inequality.

Discrete

Recommendations that digital and app delivery teams could adopt:

1. Where possible, collect, analyse, and use data on ethnicity, digital behaviours, and health outcomes. Where not possible, identify barriers and explore opportunities for how these can be overcome.
2. Better communicate to ethnic communities how data and digital tools deliver health benefits.
3. Clearly communicate hard boundaries around issues people are most concerned about, with all users - e.g. sharing identifiable data with the government.
4. Identify ways to design better feedback loops into digital services so users benefit from using and sharing data with apps.
5. Invest resources to build out data infrastructure and in-house data analytic capabilities.

Connected

Recommendations that digital and app teams need to collaboratively work with others towards:

6. NHSBT, NHSE Transformation, and NHS Digital should define and enforce new standards and best practices for internal data collection and sharing, so that linked data on health and ethnicity can be accessed to understand challenges and make service improvements. This could be part of existing initiatives such as the development of General Practice Data for Planning and Research (GPDPR).
7. NHSE and NHSBT should partner with NHS RHO to co-design data privacy guidelines with black and minority ethnic communities, ensuring clarity as well as building trust in how data would be collected and used.

Systemic

Recommendations that require a clear leadership mandate for systemic reform:

8. The Department for Health and Social Care, NHS England, and NHS Digital need to work together to define and enforce standards and a culture of compliance and ethics around data across all levels, which includes:
 - a. Ensuring that wider primary care services including GP practices, hospitals and commissioning groups collect ethnicity data consistently.
 - b. Ensuring that data is stored and shared in open, consistent and secure ways.
 - c. Investing in upskilling all levels of NHS and NHSBT staff involved in patient facing delivery of health services, on data literacy and ethical data-decision making.
9. The Health Inequalities Improvement Programme at NHSE, NHSBT, and NHS Digital should work with the NHS Race and Health Observatory to pilot and implement updated guidelines and processes for ethnicity coding in the NHS.
10. The accountability for collecting and ensuring patient ethnicity data in the NHS and NHSBT should be clarified, following guidance from the Nuffield Trust, as part of the 'Ethnicity coding in English health service datasets' report (2021).⁶ As part of their new remit to implement a population health platform, Integrated Care Systems (ICSs) can hold the accountability for collecting more consistent primary services data at the local level and be accountable for enforcing data standards for such.

Ways of working recommendations

Ensuring that delivery and leadership teams are empowered and have the right conditions in place to work towards collectively reducing ethnic health inequalities.

Discrete

Recommendations that digital and app delivery teams could adopt:

1. Build ethnically diverse digital teams
2. Invest in training that deconstructs racism, introduces anti-racist and inclusive practices. This training should lead to implementation of anti-racist practices, giving delivery teams shared frameworks to work from.

⁶ Nuffield Trust and the Health Foundation. "Quality and inequality." The Nuffield Trust, https://www.nuffieldtrust.org.uk/public/files/2020-01/quality_inequality/v2/. Accessed 6 May 2022.

3. Connected

Recommendations that digital and app teams need to collaboratively work with others towards:

4. Digital teams should partner with stakeholders, commissioners, and other organisations to identify how digital can be part of collective place-based goals to address local challenges, reduce ethnic disparities in health, and monitor outcomes.

5. Systemic

Recommendations that require a clear leadership mandate for systemic reform:

6. Ensure ethnic diversity in the NHS leadership nationally, including in organisations such as NHSBT, NHSE, and NHSD, to signal a clear commitment to address systemic racism .
7. National NHS leadership including organisations such as NHSBT, NHSE, and NHSD should promote a culture of cross-disciplinary learning, sharing, and improvement. National NHS leadership should proactively invest in digital transformation in ways that ensure inequality is intentionally addressed.
8. NHS leadership should consider new service ownership models that enable app and digital teams to work more closely with service owners and other teams to use data to understand and test new solutions along the user journey. Clear accountability along with multidisciplinary, collaborative ways of working will lead to more joined up experience for patients and better understanding of health outcomes.

