NHS RACE & HEALTH OBSERVATORY

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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TPXimpact
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Contents

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About this report

TPXimpact was commissioned by the NHS Race & Health Observatory to deliver research that can shape future digital health recommendations to reduce ethnic inequality in the usage of healthcare apps such as the NHS App, NHSBT Give Blood app, and other current and future healthcare apps. As health inequalities are shaped by wider determinants of health, addressing them requires a response beyond digital and even beyond the NHS. This report focuses on the role digital can play in understanding and addressing ethnic health inequalities. Throughout the report, when talking about 'digital', we are referring to healthcare services that are delivered through online and mobile channels. We also refer to 'digital' as an organisational strategy enabling how digital services are delivered.

TPXimpact were commissioned to deliver this report from February to June 2022. We conducted qualitative research on the experience of Black, Asian, and minority ethnic communities with digital and health services. We also spoke to teams working on the apps to understand current processes, ambitions, and constraints. Our detailed methodology can be found in the Methodology section of this report.

We drew on lessons learnt from two case studies: NHS Blood and Transplant's Give Blood app and the core NHS App. The project is not an audit or critique of the apps, which are delivered with focused remits and operational constraints. Rather, the report sets out a challenge to national NHS leadership including NHS Digital (NHSD), NHS England (NHSE), and NHS Blood and Transplant (NHSBT) in how the organisations see the potential for digital to be a force in addressing structural issues. Drawing on lessons learnt from existing apps, we have delivered recommendations for future digital health apps that look to address systemic ethnic inequalities in healthcare.

An initial goal for the project was to measure the variation in use and experience of the apps by ethnicity. However, lack of accessible quantitative data from both apps highlighted the need for improvement in data collection and processing, which is as explored in this report.

It is worth highlighting that the research was conducted after the peak of the COVID-19 pandemic, when many changes to public health services and delivery had to be made to ensure public safety and continued operations. This context inevitably shaped our findings. As the recommendations are taken forward and implemented, we recommend the NHS continues to engage both a wide group of stakeholders across the organisation as well as Black, Asian, and minority ethnic community members. We recommend further research based on this report in 18-24 months to review how recommendations have been adopted, with new data collected from current apps.

Approach to language

Following guidance from the Race and Health observatory, where there is a need to refer to more than one ethnic group at a time, the report will use terms such as 'Black and minority ethnic', 'ethnic minority', 'Black, Asian, and minority ethnic', interchangeably, to reflect the varying views of stakeholders on language and representation.[1]

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[1] NHS Race & Health Observatory. "The Power of Language." NHS Race and Health Observatory, 26 11 2021, https://www.nhsrho.org/wp-content/uploads/2021/11/NHS_RaceHealthObservatory_Terminology-consultation-report-NOV-21.pdf. Accessed 10 August 2022.

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 guidelines[2], projects such as A.T. Beacon Community Hubs,[3] and NHSBT Community Investment Scheme,[4] 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.**

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[2] Inclusive content - - - Ethnicity, religion and nationality. NHS digital service manual. "https://service-manual.nhs.uk/content/inclusive-content/ethnicity-religion-and-nationality"

[3] AT Beacon Project. "What We Do." AT Beacon Project, https://www.atbeaconproject.org/what-we-do. Accessed 1 July 2022.

[4] 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 shared[5]. 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 security[6]. 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.

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[5] 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

[6] 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) .[7]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.

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[7] 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.

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.

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.

1. Introduction

The NHS Long Term Plan[8] commits to a more concerted and systematic approach to reducing health inequalities and addressing unacceptable variation in care across ethnicities. One of the key enablers identified in the plan is digital tools. It is hoped that these digital tools will empower people and transform the way the public receives healthcare and engages with health care services. In the last 24 months, digital has been put to the test like never before. The COVID-19 pandemic simultaneously limited health care providers' ability to offer traditional face-to-face appointments and exerted pressure on the NHS to ramp up an unprecedented national vaccination programme.

While digital services are designed to improve health outcomes, the NHS also acknowledges the unintended consequences that digital transformation might have on accessibility. The NHS Digital Inclusion plan acknowledges that 'people who have characteristics that are protected under the Equality Act 2010 (age, disability, race) are less likely to have access to the internet, and the skills to use it'. How can digital tools be a force to reduce inequality, and specifically ethnic health inequality, rather than increasing it? What can we learn from the last 24 months to scale out digital delivery and investments in the future? These are some of the key questions that prompted the commissioning of this research.

1.1. Goal for this review: How can digital applications reduce ethnic inequality in health outcomes?

Digital is a broad field and while some of the recommendations within this report may have broader implications, this research is a deep dive on the lessons learnt from two patient-facing apps: NHS Blood and Transplant's Give Blood app and the NHS App.[9] The project is not intended as an audit or critique of current app teams. Rather, we draw on the experiences, successes, and challenges from these apps to set out a challenge to the national NHS leadership. It's important to note here that both NHSBT and the NHS App work in fundamentally different ways. Even so, both offer valuable learnings in terms of their offering and structure that will help shape recommendations for the next generation of apps and digital services, across the two organisations as well as wider healthcare services.

- Launched in 2014, the Give Blood app allows people to search for and book appointments to give blood, as well as manage their own donor details. It also provides screening information on who can donate blood. It is entirely owned and operated by NHSBT.[10]

- Launched in 2019,[11] the NHS App was designed to provide a point of access into multiple services for users. It was built under commission from NHSE to initially include: booking and managing appointments at GP practice, ordering repeat prescriptions, securely viewing GP medical record, checking symptoms using NHS 111 online and the Health A-Z feature on the NHS website, registering as an organ donor, choosing whether the NHS uses a person's data for research and planning.[12] The NHS App is one way through which patients can access account services (the other being the NHS website). In 2021, the NHS COVID Pass service was integrated into the NHS App and constantly kept updated to meet the changing policy requirements during the pandemic.[13]

We were particularly interested in how the COVID-19 pandemic, and the changes it caused, affected the relationship people from minority ethnic groups had with the NHS and digital services.

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[11] NHS England. "NHS England » NHS App begins public rollout." NHS England, 23 January 2019, https://www.england.nhs.uk/2019/01/nhs-app-begins-public-rollout/. Accessed 1 July 2022.

[12] From comments from NHSD team.

[13] From comments from NHSD team.

1.2. Approaching the problem from different perspectives

Given the complexity of the problem, to identify the most pertinent challenges and potential solutions, we explored the lessons learnt from different perspectives (detailed methodologies are elaborated in Methodology section below). These included:

- **Expert/system perspective:** We spoke to academic experts and conducted a literature review of relevant studies, in order to frame the relationship between apps, digital, and ethnic health inequality.

- **App team perspective:** We engaged with stakeholders and team members working closely on the two apps in order to understand the lessons learnt, constraints, and successes in delivering the apps so far.

- **Community perspective:** We conducted research with Black, Asian, and minority ethnic community members, in order to understand people's unique experience with the apps.

- **Data perspective:** We reviewed available data to explore the difference in usage of the two apps by ethnicity of users. Unfortunately, data was not accessible to give quantitative evidence. We explore these challenges around data and their potential implications later in this report.

Across these streams of research, we focused on two areas where there is visible ethnic health inequality, that are also related to the remits of the two apps:

- **Blood donation:** Fewer than 5% of blood donors from Black, Asian, and minority ethnic communities donated blood in a year. [14]There is a particular shortage of donors of Ro blood type who are typically from Black or South Asian backgrounds.[15]

- **Vaccinations:** The ethnic groups with the lowest proportion of people who had received three COVID-19 vaccinations were Black Caribbean (33.9%), Pakistani (37.8%) and Black African (37.9%).[16]

1.3. Outcomes

The research, engagement, and discussions throughout the project have culminated in a series of recommendations for a future generation of healthcare apps, focusing on design, data, and ways of working. These recommendations have been categorised as discrete, connected, and systemic with the recognition that health inequality is a deep-rooted and systemic issue, requiring change from leadership cutting across the NHS. We have built on the existing NHS Design Principles to frame an actionable design checklist for future apps, helping to bring issues of equity and equality to the forefront of future design efforts. These principles can be found at the end of this report.

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[14] NHSBT. (n.d.). Black, Asian and minority ethnic communities - NHS Blood Donation. Give Blood: Demand for different blood types. Retrieved May 6, 2022, from https://www.blood.co.uk/why-give-blood/demand-for-different-blood-types/black-asian-and-minority-ethnic-communities/

[15] NHSBT. (n.d.). Black, Asian and minority ethnic communities - NHS Blood Donation. Give Blood: Demand for different blood types. Retrieved May 6, 2022, from https://www.blood.co.uk/why-give-blood/demand-for-different-blood-types/black-asian-and-minority-ethnic-communities/

[16] Nafilyan, V., Dolby, T., & Health.Data@ons.gov.uk. (2022, January 20). Coronavirus and vaccination rates in people aged 18 years and over by socio-demographic characteristic and occupation, England. Office for National Statistics. Retrieved May 6, 2022, https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/coronavirusandvaccinationratesinpeopleaged 18yearsandoverbysociodemographiccharacteristicandoccupationengland/8december2020to31december2021

2. Methodology

Given the project's timeframe and goal to deliver actionable digital design guidelines, we adopted a targeted approach that iteratively built on evidence through a literature review, interviews, focus groups and workshops. As part of UK GDPR, individuals from NHSE, NHSBT and NHSD who have taken part in this research are not named but are referred to as 'team members'.

2.1. Expert interviews and literature review

To frame the research and build on existing work, we started by reviewing existing studies and policy on the topic, as well as by speaking to academic and community experts working on the topic in one to one sessions. Our starting point was the NHS RHO's own Rapid Evidence Review on Ethnic Inequalities in Healthcare (published February 2022).

Because of the relatively new context of digitalised health, the existing literature on ethnicity disparities of health outcomes was limited. Literature on the impact of the COVID-19 pandemic was even more limited, as the pandemic was still ongoing. We supplemented academic literature with news reports, as well as NHS Digital's and NHSBT's own published research and conversations with leading experts — including epidemiologists, researchers on race and health, community health experts and community organisers.

This literature review helped us identify the most important themes connecting digital usage to health outcomes and ethnicity, enabling us to frame more targeted conversations with NHS teams and design focus groups.

2.2. Team engagement

We reached out to a wide range of team members working on the NHS App and NHSBT Give Blood app based on recommendations from their leadership. Prior to these conversations, we sent an email introducing the purpose of the research, along with qualitative and quantitative questions for the team (included in the appendix). We invited team members who responded and were available to take part in virtual group interviews. The purpose of the group interviews was to understand how teams consider issues of health disparity and ethnic inequality in their work today, and to understand whether data existed and how it was used to measure usage by ethnicity. In total, we spoke to 20 staff members across NHS Digital and NHSBT app teams, through 5 group and individual virtual calls between January 2022 and February 2022. We followed up these interviews with further requests for any data, insights, or evidence. We also spoke to 4 stakeholders and researchers working on Customer Experience at NHS England and Improvement, in 2 group calls virtually.

We were not able to speak to current team members working on the COVID-19 App because it was commissioned by the Department of Health and Social Care rather than the NHS, and also because of organisational changes within the team. This meant that we were not able to receive clearance and access to conduct the research within the given project timeframe.

Additionally, we shared and discussed our early findings with 20 experts as part of the NHS Race and Health Observatory's RHO Digital and Data Working Group in February 2022.

2.3. Community focus groups

We designed focus groups to speak with Black African, Black Caribbean, Pakistani and Bangladeshi participants in order to understand their experiences and perspectives on the NHS and its services, including COVID-19 vaccinations, blood donation, usage of NHS apps, and data sharing.

We chose to prioritise these ethnic groups because they are disproportionately impacted by blood donation shortage and low rates of vaccination. The experiences of different ethnic groups are unique and rather than attempting to generalise the experience of diverse minority ethnic communities, we focused on several specific communities with heightened needs, a standard user research approach.

We conducted four focus groups with a total of 16 participants (eight Black African/Caribbean and eight Pakistani/Bangladeshi participants). Our primary goal in recruitment and planning of the focus groups was to be as inclusive as possible. Two focus groups were in-person and two were virtual, as we wanted to include those based outside London. We held two sessions in the evening so people who work during the day could join. The in-person focus groups were held in a public library and a community centre in Southwark and Newham (London) as these boroughs have some of the highest density of Black and South Asian communities in the UK.

We recruited a spread of genders, ages and sexualities as our priority was a diverse mix of views. We also prioritised lower ranges of income as voices of these groups are often underrepresented. Participants had a mixed spread of health behaviours on vaccinations, as we wanted to facilitate conversations exploring different perspectives. We recruited for a range of confidence with technology and screened for varied app use.

2.4. Shareback sessions and report feedback

After synthesising insights from all three streams of research, we held shareback sessions where we invited a blend of digital team members from NHS Digital, NHSX (now NHSE), NHSBT, and NHS RHO to give feedback and build on our recommendations. 22 team members from the two App teams were invited to attend 4 virtual shareback sessions in the week of April 18th 2022 (with the option to suggest alternative times). In total, 12 team members attended virtual workshops where interim findings and initial recommendations were shared and discussed.

The draft report has also been shared with senior stakeholders at NHS Digital, NHSBT as well as NHS RHO steering group members, including academics and experts working in digital or healthcare, for further refinement and feedback. In total, 12 people across NHSD, NHSBT, and NHSE/I were directly invited to comment on drafts of this report, in four rounds of feedback in May and June 2022. The NHSBT and NHSD teams were also given options to circulate and collect feedback from their wider teams.

2.5. Limitations

This report looked to bring together vast topics such as systemic inequalities, digital apps, and healthcare in a time-bound scope to create actionable guidelines. The research methods and sample size were purposefully selected to be targeted so that this aim could be achieved. A key challenge for the research team was the lack of accessible quantitative data from both apps. This was mitigated by conducting a comprehensive literature review and understanding of the constraints and opportunities for how digital and app teams design and deliver digital services and apps today. Another challenge the research team experienced is that the NHS has a complex organisational structure made up of multiple organisations. Many topics covered in this report touch on a wide range of remits, roles, and responsibilities held by individuals sitting across different NHS departments and organisations.

It is also worth highlighting that this research was conducted after COVID-19 pandemic restrictions were lifted. As the recommendations are taken forward towards implementation, we recommend the NHS continues to engage both a wide group of stakeholders across the organisation as well as Black, Asian, and minority ethnic community members. We recommend further research based on this report in 18-24 months to review how recommendations have been adopted, together with new data collected from current apps.

3. The potential for digital apps in reducing ethnic health disparities

This section explores ethnic inequalities and digital healthcare by bringing together academic literature, news reports, and insights from expert interviews and focus group sessions. It unpacks structural inequalities and dives into how ethnic inequality in health was prevalent before the pandemic, with discrimination in healthcare being difficult to prove. The section also highlights how digitalisation has the potential to reach diverse communities but also holds risks for Black, Asian, and minority ethnic communities.

3.1. Health inequality is deep rooted, pervasive, and systemic

Ethnic inequality in health was prevalent long before the pandemic

13% of the UK's population belong to a Black, Asian, mixed or other ethnic group. [17]As at the 2011 Census, the most ethnically diverse region in England and Wales was London, where 40.2% of residents identified as being part of one of these groups.[18]

Ethnic inequality in health is a systemic and persistent issue for the NHS. NHS RHO's own rapid review published earlier this year (2022) highlighted widespread and deep-rooted inequalities experienced by members of these diverse groups across five key areas of the NHS: mental health, maternity and neonatal healthcare, digital access to healthcare, genetic testing and genomic medicine and the NHS workforce.

The study reviewed 178 studies from over 13000 papers over a 10-year period and ran a survey and focus groups with people working with ethnic minority communities. The review found the following:

- In mental health services, there was robust evidence of compulsory admission to psychiatric wards, particularly affecting Black groups, but also Mixed Black & White groups and South Asian groups. There was also evidence of harsher treatment for Black groups in inpatient wards, e.g. more likely to be restrained in the prone position or put into seclusion[19].
- When it comes to accessing maternal or neonatal care, qualitative studies reported that ethnic minority women often feel underserved and have a high prevalence of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity. The RHO review also spoke to how cultural insensitivity and lack of accommodation of cultural and religious needs is a further dimension of women's negative experiences.

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[19] Hackett, R. A., Ronaldson, A., Bhui, K., Steptoe, A., & Jackson, S. E. (2020, November 18). Racial discrimination and health: a prospective study of ethnic minorities in the United Kingdom - BMC Public Health. BMC Public Health. Retrieved May 6, 2022, from https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09792-1

- With regards to communication, the review showed how for some groups of women, poor communication could be linked to lack of English language skills and inadequate provision of interpreter services.[20]

The pandemic has further highlighted ethnic health inequalities across the country. There were visible discrepancies in both COVID-19 mortality and vaccine uptake within different ethnic minority communities. For example:

- Ethnic groups with the most excessive COVID-19 mortality rates were Bangladeshi and Pakistani groups.[21]
- The lowest proportion of people who received three vaccinations were Black Caribbean (33.9%), Pakistani (37.8%) and Black African (37.9%).[22]
- Bias designed into medical devices such as pulse oximeters made them less sensitive on darker skin colours[23] which likely contributed to unnecessary deaths due to COVID-19.

While the causes of these disparities are dependent on a number of factors, it is symptomatic of how broader structural and health inequalities manifest during a public health crisis.[24]

The issues represented above demonstrate just how widespread and entrenched ethnic discrimination and disparities are in healthcare, including the NHS and NHSBT. Despite these inequalities being increasingly highlighted in popular media, the personal and often isolated ways in which a person experiences healthcare mean it can be difficult for patients to know or prove that they are receiving differentiated care.

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[20] Kapadia, D., Zhang, J., Salway, S., Nazroo, J., Booth, A., Villarroel-Williams, N., Bécares, L., & NHS Race and Health Observatory. (2022, February). Ethnic Inequalities in Healthcare: A Rapid Evidence Review. NHS Race and Health Observatory. Retrieved May 6, 2022, from https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf

[21] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles updatingethniccontrastsindeathsinvolvingthecoronavirusCOVID19englandandwales/8december2020to1december2021 #:~:text=After%20adjusting%20further%20for%20other,the%20White%20British%20ethnic%20group.

[22] Ahmed, T., Drummond, R., & Office for National Statistics. (2022, January 26). Updating ethnic contrasts in deaths involving the coronavirus (COVID-19), England. Office for National Statistics. Retrieved May 6, 2022, from https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/updatingethniccontrastsindeathsinvolvingthecoronavirusCOVID19englandandwales/8december2020to1december2021

[23] NHS Race and Health Observatory. (2021, April 14). Pulse Oximeter Bias Highlighted in Rapid Review. NHS Race and Health Observatory. Retrieved May 6, 2022, from https://www.nhsrho.org/publications/pulse-oximeter-bias-highlighted-in-rapid-review/

[24] Patel, P., Hiam, L., Sowemimo, A., Devakumar, D., & McKee, M. (2020). Ethnicity and COVID-19. BMJ, 369(m2282). doi:10.1136/bmj.m2282

Discrimination is difficult to prove, creating doubt and emotional trauma for individuals and communities

In the focus groups we conducted with Black and South Asian community members, despite general appreciation for the NHS' role in society, most participants talked about feeling mistreated, being underserved, or feeling ignored when seeking help from NHS primary services, particularly during the pandemic.

For example, one participant said:

> "I don't trust the health system, I don't think healthcare professionals know what's best for me. I feel I've been gas-lit a lot…I had some consultants [for polycystic ovary syndrome], and male doctors said some not very nice things…very sexist, very racialised…I've experienced this over the years, it hasn't got better."
>
> \- participant 1 (female, Black British, 29)

Another shared his experience being ignored by the NHS while suffering with COVID-19:

> "It was a disaster…there was a lack of support - I kept calling the GP's number and couldn't get through. I am asthmatic so quite poorly and was off sick for two months. I was struggling to breathe and couldn't get through to get antibiotics or an appointment. I've had to learn to self-manage."
>
> \- participant 5 (male, Black Caribbean, 49)

Despite this, people had no way of comparing their own experiences to others to know whether their own experiences were unique or universal, leading to lingering concerns and a further emotional toll. One participant spoke about his partner's negative experience giving birth:

> "When my wife was in labour, the way they were treating her was not right. But I don't know if that's down to race. There's been things I've read about Black women, doctors thinking they have higher pain thresholds. But I don't know if that was the case with our experience."
>
> \- participant 12 (male, Black British, 34)

To further complicate matters, minority Black and South Asian populations are heavily concentrated in deprived boroughs, particularly in London. [25]These deprived and densely populated boroughs further lack in the quality of care including spending longer in A&E and having a worse experience of making a GP appointment, leading to poorer health outcomes.[26]

In focus groups for this review, many participants spoke about longer waiting times and difficulties getting GP appointments but explained the poor treatment was the result of the geographic location they were in rather than due to ethnicity. As one participant highlighted:

> "In London it's difficult to get appointments. My daughter moved to Warwick for university. When she needed medical care, she was able to ring up, and got listened to straight away. She wasn't even in their books, yet got straight through."
>
> \- participant 6 (female, Black Caribbean, 52)

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[25] GOV.UK. (2020, June 16). People living in deprived neighbourhoods - GOV.UK Ethnicity facts and figures. Ethnicity facts and figures. Retrieved May 6, 2022, from https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/people-living-in-deprived-neighbourhoods/latest

[26] Nuffield Trust and the Health Foundation. (n.d.). Quality and inequality. The Nuffield Trust. Retrieved May 6, 2022, from https://www.nuffieldtrust.org.uk/public/files/2020-01/quality_inequality/v2/

This illustrates how structural racism entangles with other social, geographical, and cultural conditions in complex ways, making it difficult to spot.

Overall, people often felt that they had no choice but to accept their own lack of power to improve the healthcare quality they received. Even when patients knew that they had been mistreated by NHS clinicians, they did not know how to or think they had the power to make complaints. One woman needed urgent brain surgery and this information was not shared with her.

> "I had a brain haemorrhage in 2012. The following year, I was having some niggly problems and was sent to the local hospital for scanning... They didn't update me or my specialist hospital on the results. Finally I got through, they did more scans, then by coincidence I had a pre-booked appointment for the week later. I went, only for them to tell me they'd found another aneurysm and I needed brain surgery…. I'd been walking along with this bomb in my head and no one told me."
>
> - participant 6 (female, Black Caribbean, 52)

Although she was shocked and scared, the participant did not pursue legal action:

> "They neglected to tell me something which could have caused me to die. In the end, I decided to not pursue making any complaints or investigations and keep the medical team on my side as the same surgeon would perform surgery on me. I feel like they have been quite neglectful, but you choose your battle… I had to learn to be my own advocate."
>
> - participant 6 (female, Black Caribbean, 52)

These repeated incidents over the course of an individual's life creates stress and lack of psychological safety when it comes to receiving healthcare. As similar negative experiences are shared across communities and memory is passed down from generation to generation, it shapes into an inherited, collective trauma, leading to a lack of trust between organisations and communities.

Black and minority ethnic communities experience structural inequalities and hostility in all spheres of life, sometimes due to intentional policy

Minority ethnic citizens face discrimination in all spheres of life: at work, in the justice system, with police, and immigration. The McGregor-Smith Review (2020) found that professionals from Black and minority ethnic backgrounds experienced discrimination in every stage in the workplace. [27]Wider government policies particularly around policing and undocumented immigration also contribute to a hostile environment for these communities - for example, the 2019/20 data indicates that Black people were about 5.7 times more likely to have force used on them than White people.[28]

While some examples of discrimination are unintentional, discrimination is also the result of intentional policy. Changing regulations have now placed a legal duty on GP practices and other primary care services to identify and report those not able to provide their eligibility for free care. Not only will patients be charged for care, but personal details shared with Immigration Enforcement may result in the patients' deportation[29]. Fear and mistrust of the NHS has led migrants to evade seeking healthcare for fear of being charged or fear of their data being shared with Immigration Enforcement.[30]

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[27] The McGregor-Smith review. (n.d.). Race in the workplace. Retrieved May 6, 2022, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/594336/race-in-workplace-mcgregor-smith-review.pdf

[28] HMICFRS. (2021, February 26). Disproportionate use of police powers: A spotlight on stop and search and the use of force. Criminal Justice Inspectorates. Retrieved May 6, 2022, from https://www.justiceinspectorates.gov.uk/hmicfrs/wp-content/uploads/disproportionate-use-of-police-powers-spotlight-on-stop-search-and-use-of-force.pdf

[29] Worthing, Kitty et al. "Patients or passports? The 'hostile environment' in the NHS." Future healthcare journal vol. 8,1 (2021): 28-30. doi:10.7861/fhj.2021-0007.

[30] New Economics Foundation, Button, D., Salhab, A., Skinner, J., Yule, A., & Medien, K. (2020, October). PATIENTS NOT PASSPORTS: LEARNING FROM THE INTERNATIONAL STRUGGLE FOR UNIVERSAL HEALTHCARE. New Economics Foundation. Retrieved May 6, 2022, from https://neweconomics.org/uploads/files/NEF_Patients-not-passports.pdf

The lack of trust that results from these policies impacts not only illegal immigrants, but creates a hostile environment that disproportionately impacts all migrant communities and minority ethnic communities. The compounded impact of unequal treatment from almost all public and private sector institutions, across all spheres of life, creates a heightened weariness, mistrust, and places a disproportionate burden on minority ethnic communities.

Understanding this context is necessary for designing healthcare services that support all patients equally. To ensure our services reach people equally, we need to focus efforts equitably to repair trust and reach out with more support to those who have been systemically underserved and marginalised in the past, thus actively reducing inequality in healthcare services. As mistrust and discrimination is an entrenched social phenomena. We cannot expect any single digital tool to resolve this. Digital needs to be part of a wider concerted effort to rebuild trust and create that equity.

3.2. Digital has the potential to reach diverse communities but also to further exclusion

Digital transformation is an NHS priority accelerated by the pandemic

Digital health is a priority for the NHS, with the NHS Long Term Plan including a goal for the NHS to operate on a digital-first basis by 2029.[31]

The COVID-19 pandemic rapidly accelerated the need to meet these digital goals and caused a shift towards the remote delivery of care. During the pandemic, it became a more common practice for GPs to offer phone consultations and schedule appointments via online systems. The NHS App recorded over 28 million sign-ups[32] since its launch, with the NHS App becoming the most downloaded free iPhone app in England in 2021. The NHSBT App also has ambitious plans to extend its digital service offerings with features such as donation history and viewing suggested venues.[33]

Black, Asian, and minority ethnic communities are open to digital solutions

Four studies[34] reviewed by the NHS RHO documented few ethnic inequalities in attitudes towards using digital health apps. The rapid review concluded that ethnic minorities and White participants were generally equally comfortable using these apps.[35]

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[31] NHS. (n.d.). Chapter 5: Digitally-enabled care will go mainstream across the NHS. NHS Long Term Plan. Retrieved May 6, 2022, from https://www.longtermplan.nhs.uk/online-version/chapter-5-digitally-enabled-care-will-go-mainstream-across-the-nhs/

[32] As of end May 2022. Data from NHS App team.

[33] NHSBT. "The NHS Give Blood app - NHS Blood Donation." Give Blood, 25 May 2022, https://www.blood.co.uk/the-donation-process/the-nhsgiveblood-app/. Accessed 1 July 2022.

[34] Partially because of the relatively new history of digital and remote care, and the fact that these tools are rapidly changing, there are fewer recent studies done on the linkage between digital tools and health inequality.

[35] Kapadia, Dharmi, et al. "Ethnic Inequalities in Healthcare: A Rapid Evidence Review." NHS Race and Health Observatory, February 2022, https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf. Accessed 6 May 2022.
There was some evidence that ethnic minority participants might use apps less frequently and those of older age may be more affected by digital exclusion due to lack of access to devices.

Statistics on internet usage has also revealed that ethnic minority communities are more frequent users of the internet and mobile phones than the national average. According to data from the Office of National Statistics, in 2018 the percentage of internet non-users within Black communities (8.2%), Pakistani communities (8%), and Bangladeshi communities (5.2%) were lower than the national average (10%), suggesting that digital exclusion is less of an issue within ethnic minority communities. Government data on internet usage suggest a similar trend as the percentage of Black and Asian people aged 16 and over who had used the internet in the past 3 months were 92.4% and 92.8% respectively, higher than national average (90.8%). [36]Likewise, data from Ofcom shows that Black and Asian people use more mobile phone data per month than the average British citizen.

From these existing statistics, it does not appear that a move towards using more digital channels might disproportionately exclude people of Black and minority ethnic groups. While digital exclusion is a valid concern that needs to be taken into consideration, it is not more prominent in minority ethnic groups than the national average, and therefore it is not a primary focus for our report.[37]

Digitalisation holds potential benefits as well as risks for Black, Asian, and minority ethnic communities

From an NHS internal operations perspective, the case for investing in digital is clear. A report commissioned by then Secretary of State Matt Hancock MP revealed that digital automation can free up to 31% of GP time – equivalent to £962m – due to improved productivity, time that could be reinvested in patient care.[38]

There are also potential benefits to patients too. Done right, patient-facing customer applications can empower patients by saving time, providing more access to information, and setting up a strong partnership with healthcare providers.[39]

However, there are valid concerns from medical professionals, civil society, and community groups that digitalisation may further existing health inequality. In stakeholder engagement workshops conducted by the Race Equality Foundation and The Ubele Initiative NHS RHO’s Rapid Evidence Review, experts and community members were highly concerned that digitalisation would further increase difficulties in accessing health appointments, increase tendency for miscommunication in digital appointments, and lead people to disengage with services. Those who speak English as a second language, people of older age and lower income backgrounds were seen to be especially at risk.

At this moment, it is neither possible nor productive to draw clear cut generalisations on whether digital is good or bad for minority ethnic communities. Longitudinal research and data are either not available or not sufficiently robust to meaningfully draw conclusions on the impact of digital applications on overall health inequality. Furthermore, government digital tools in healthcare are still in early stages; the NHS App for example, is only 3 years old.

The biggest potential that digital tools have is they can be quickly changed and adapted based on understanding of user needs, and it is important that as they evolve, they be used to reduce inequality rather than to inadvertently increase it.

[36] GOV.UK. “Internet use.” Ethnicity facts and figures, 5 September 2019, https://www.ethnicity-facts-figures.service.gov.uk/culture-and-community/digital/internet-use/latest. Accessed 6 May 2022.

[37] Ofcom. “Ethnic minority groups love their gadgets and home technology.” Ofcom, 20 August 2013, https://www.ofcom.org.uk/about-ofcom/latest/media/media-releases/2013/ethnic-minority-groups-love-gadgets-and-technology. Accessed 6 May 2022.

[38] Pulse. “Automation could free up 31% of GP time, says Hancock report.” Pulse Today, 1 May 2019, https://www.pulsetoday.co.uk/news/technology/automation-could-free-up-31-of-gp-time-says-hancock-report/. Accessed 6 May 2022.

[39] Hyland. “How technology can empower the patient as partner.” Healthcare IT News, 1 October 2020, https://www.healthcareitnews.com/news/emea/how-technology-can-empower-patient-partner. Accessed 6 May 2022.

Digital can potentially amplify or reduce ethnic inequality - it all depends on the implementation

Technology is often a multiplier - its biggest strengths being the ability to make existing processes and services faster and more efficient, as well as increasing the reach of services. When it comes to inequality, technology has the potential to either increase inequalities or reduce them. Key to understanding technology's role are the goals, considerations, and intentions that underpin how a certain technology was designed and implemented, including processes used, the users involved and the quality of execution.

Since all technology is created by humans, it often absorbs the structural inequalities, biases and exclusions prevalent in wider society to create unintended consequences unless proactively considered from the start. For example, an established body of evidence has emerged on biases with facial recognition technology. The landmark 'Gender Shades' project (Buolamwini and Gebru, 2018) [40]found that algorithms that boasted high classification accuracy (over 90%) did not, in fact, achieve universal outcomes. The research exposed divergent error rates across demographic groups, with the poorest accuracy consistently found in subjects who were female, Black, and 18-30 years old.

Earlier, we discussed how biases baked into the design of pulse oximeters could have potentially resulted in avoidable COVID-19 deaths for minority ethnic patients. [41]The same is also true of digital health applications which, unless proactively managed, are likely to recreate the structural and systemic biases which exist in healthcare in the NHS. An example of this comes from NHSBT, where there was a higher rate of deferrals or disqualifications to donate blood for ethnic minorities, particularly Black potential donors, based on specific qualification questions. This was leading to disparities in the use of the blood donation service, before a proactive policy change in 2021 that countered this bias. [42]Another example is from the NHS Digital team, who recognised that only showing skin symptoms on white skin, on the NHS website, was both a health inequality and a clinical safety issue. This was because people whose skin tone was not represented in the NHS content did not have the same opportunity as people with white skin to recognise symptoms and understand what they needed to do next. [43]The team has since worked on this issue and turned their learnings into guidance for the NHS Digital service manual.[44]

When digital healthcare content is not designed for an ethnically diverse audience, it has the potential to exclude them by not taking their needs into account. This could include either not having enough clinical advice about specific healthcare issues that are more pervasive in an ethnic minority sub-group or more generic healthcare advice that only speaks to a predominant population such as skin symptoms that only demonstrate on white skin tones. If digital health apps are not designed intentionally to challenge existing racial bias, they are likely to sustain or even enhance the entrenched, structural racism that has so far resulted in unequal health outcomes in the NHS, including NHSBT.

As digital continues to evolve and mature in the NHS, including NHSBT, it is fundamental that the organisations are committed to investing in digital, including patient facing apps, as critical frontline tools to proactively reduce inequality.

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[40] Buolamwini, Joy, and Timnit Gebru. "Gender Shades: Intersectional Accuracy Disparities in Commercial Gender Classification*." Conference on Fairness, Accountability, and Transparency, vol. Proceedings of Machine Learning Research 81:1–15, 2018, http://proceedings.mlr.press/v81/buolamwini18a/buolamwini18a.pdf. Accessed 6 May 2022.

[41] Dada, Olamide, and NHS Race and Health Observatory. "Pulse oximetry and racial bias: Recommendations for national healthcare, regulatory and research bodies." NHS Race and Health Observatory, 15 March 2021, https://www.nhsrho.org/wp-content/uploads/2021/03/Pulse-oximetry-racial-bias-report.pdf. Accessed 6 May 2022.

[42] Department of Health and Social Care, Maria Caulfield MP, and The Rt Hon Sajid Javid MP. "Blood donation to be made more inclusive." GOV.UK, 11 October 2021, https://www.gov.uk/government/news/blood-donation-to-be-made-more-inclusive. Accessed 1 July 2022.

[43] Smith, Rhiannon. "Making content about skin symptoms more inclusive." NHS Digital, 30 July 2021, https://digital.nhs.uk/blog/design-matters/2021/making-content-about-skin-symptoms-more-inclusive. Accessed 1 July 2022.

[44] NHS Digital. "Inclusive content - - - Skin symptoms." NHS digital service manual, https://service-manual.nhs.uk/content/inclusive-content/skin-symptoms. Accessed 1 July 2022.

Digital cannot be an isolated solution, it needs to be part of broader system change

Since ethnic health inequality is systemic and pervasive, no single digital solution or app can resolve this. Rather, digital and apps have the potential to be part of joined-up services that can be deployed as a direct interface to millions of users. Together with a coherent strategy, to actively reduce ethnic health disparities, these can reach out to diverse patients from different ethnic backgrounds. This coherent approach will help the NHS and NHSBT achieve the broader systemic goal of driving equitable and better health outcomes for all.

3.3. National NHS leadership needs to proactively invest in digital transformation in ways that ensure inequality is intentionally addressed

The role digital will have on ethnic health inequality will depend on the way digital is designed and delivered, as part of a wider ecosystem of services. There is a potential for digital to play an active role in reaching out to diverse communities to help the NHS achieve a broader systemic goal of driving equity and health outcomes.

Government digital tools in healthcare are still in their early stages today. As digital across the NHS and NHSBT matures and apps evolve, it is fundamental that the NHS, including NHSBT, are willing to invest in digital transformation - including transforming tools, culture, and processes to proactively reduce inequality. The key to unlocking this potential will be how the apps are designed together with different patient and community groups upfront, the purpose and remit given to app teams, how features are prioritised, and more importantly, how digital sits along with wider service delivery and organisational change.

In the next section, we look in more detail at current lessons from the NHS Give Blood app and NHS App to start shaping an understanding for how a future generation of these healthcare apps can play a more proactive role in driving equity in healthcare.

4. Lessons learnt from the NHS App and the NHS Give Blood app

Digital, data, and IT are all central parts of how the NHS and NHSBT operate. Different departments, GP practices, and commissioning groups rely on different in-house or externally provided technologies to support doctors, patients, and other administrative staff. Some of these technologies are patient-facing, some are staff facing and administrative, and some help automate clinical processes. Because of their diversity, is it not possible to generalise across all instances of digital usage in the NHS and NHSBT.

This section provides a deep dive into two patient-facing apps, the NHS App and the NHS Give Blood app. We look specifically at learnings from the delivery of apps and review key challenges and opportunities from the perspective of ethnic health inequality. It's important to note here that both NHSBT and the NHS App work in fundamentally different ways, yet offer valuable learnings in terms of their offering and structure that will help shape recommendations for the next generation of apps and digital services, across the two organisations as well as wider healthcare services.

4.1. Lessons learnt from delivering NHSBT's Give Blood app

NHS Blood and Transplant (NHSBT) is a specialist health authority in England and Wales dedicated to saving and improving lives through the wide range of blood, organ or tissue services that it provides to the NHS. The organisation's key role is to improve the supply of donated blood, organs, and tissues nationally. The Give Blood app launched by NHSBT in 2014 was an organic extension of an existing service on the Giveblood website.[45]

The app's purpose is to make booking and checking up on appointments more convenient and consequently encourage more frequent donations. It achieves this by streamlining the patient experience and stripping back any broader content that can be found on the website. The app is mainly downloaded and used by frequent blood donors - its primary use is therefore a retention tool rather than a new donor acquisition tool.[46]

Levers of success: Measurable goals and clear service ownership

When it comes to reducing ethnic inequality, NHSBT has a clear goal of increasing and retaining non-White blood donors. [47]This is because there is a clinical shortage for some rare blood types, which are more common among particular ethnic groups. Specifically, there is a need for more Black donors to meet the growing demand for the Ro subtype, which is a good match for patients with sickle cell disease. The scale of this challenge was calculated to be considerable, with at least 40,000 new Black donors needed to dramatically increase the Ro blood donor base from 17,000 to over 35,000.[48]

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[45] From the NHSBT team interview.

[46] From the NHSBT team interview.

[47] NHSBT. "Why Black, Asian and minority ethnic donors are needed." NHS Blood and Transplant, https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/key-messages-and-information/why-black-asian-and-minority-ethnic-donors-are-needed/. Accessed 1 July 2022.

[48] NHSBT. "Call for black donors to join the growing numbers saving lives giving blood and organs this Black History Month." NHS Blood and Transplant, 8 October 2018, https://www.nhsbt.nhs.uk/news/call-for-black-donors-to-join-the-growing-numbers-saving-lives-giving-blood-and-organs-this-black-history-month/. Accessed 6 May 2022.

The clear remit has helped NHSBT prioritise its data collection in order to be able to track feedback from Black, Asian, and minority ethnic donors throughout the patient journey. [49]A positive example is that quantitative and qualitative feedback revealing why Black donors drop off in the screening process due to insensitive questions have helped the NHSBT team redesign screening questions in order to reduce dropout rates. [50]NHSBT is also empowered to make these changes as it owns the end-to-end journey of the blood donation user experience.[51]

Challenge for the team: Limited functionality of the app

The NHSBT has a range of investments and initiatives in place to target more Black, Asian, and minority ethnic donors. These include improving the end-to-end donor experience for these groups, an advocacy/ambassador programme, and 'Member-get-Member' initiatives to encourage donors to 'bring a friend'. [52]However, currently these are not linked to or supported by the NHSBT App.

The NHSBT App today is primarily focused on improving the booking experience for frequent donors, and the team is aware that non-White donors are less likely to download the app than White donors. [53]This is not surprising given that only 5% of blood donors are from Black, Asian and minority ethnic communities. [54]Black and ethnic minority donors are also harder to convert to regular donors: only one in twenty black people who register as a potential blood donor will go on to become a regular donor, compared to one in ten of all donors.[55]The current remit of the App can make it challenging for the team to help drive improvement in overall Black and minority ethnic engagement with blood giving.

Challenge for the team: Lack of ability to analyse data

The app collects and has access to personal data through their donor profiles and is also linked to a monthly pulse survey that collects donor feedback on the app. Examples of data collected by the app include demographic, clinical, and behavioural data, such as blood type, ethnicity, age, number of log-ins, appointment bookings, self-deferrals, as well as answers to the monthly pulse survey.[56]
In the past, NHSBT have used insights drawn from customer feedback in the monthly pulse surveys and other channels to iterate and build on their service. However, despite having this data, NHSBT has struggled with both human and processing capacity to analyse it in a timely and actionable manner.

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[49] From the NHSBT team interview.

[50] From the NHSBT team interview.

[51] From the NHSBT team interview.

[52] From the NHSBT team interview.

[53] From the NHSBT team interview. While this reflects team sentiments, we could not access the data backing this.

[54] NHS Blood and Transplant. "Black, Asian and minority ethnic communities - NHS Blood Donation." Give Blood: Demand for different blood types, https://www.blood.co.uk/why-give-blood/demand-for-different-blood-types/black-asian-and-minority-ethnic-communities/. Accessed 6 May 2022.

[55] From the NHSBT team interview.

[56] From the NHSBT team interview.

[57] Throughout the duration of this study, the NHSBT team were not able to access and analyse data in order to produce and examine trends on longitudinal differences in app and website usage by ethnicity. This was in part because the dataset was poorly organised, making it challenging to extract and process information and insights for timely use.[58]

Challenge for the team: Lack of collaboration between clinical and digital

From interviews with staff, NHSBT has identified an opportunity for clinical and digital teams to work better together to create a smoother experience for donors and to share learnings across the patient journey. During the COVID-19 pandemic, there were inconsistencies between language on the apps and the guidance that clinicians were giving donors over the phone on updated blood donation policy. [59] This led to confusion for donors, resulting in potential dropouts.

4.2. Lessons learnt from delivering the NHS App

The NHS App team operates in a very different context to the NHSBT app team. Launched in 2019, the NHS App was designed to provide a point of digital access into multiple existing services for users, by working across different systems. It was built under commission from NHSE to initially include: booking and managing appointments at GP practices; ordering repeat prescriptions; securely viewing GP medical records; checking symptoms using NHS 111 online and the Health A-Z on the NHS website; registering as an organ donor; and choosing whether the NHS uses a person's data for research and planning. [60] In addition to mobile, the App can also be accessed through a browser based version on the NHS website. In 2021, the NHS COVID Pass service was integrated into the NHS App and constantly kept updated to meet the changing policy requirements during the pandemic. The App is one point of access to the COVID Pass.[61]

Since its launch, the App has recorded over 28 million sign-ups, [62] 20.3 million repeat prescriptions,[63] and 1.8 million GP appointments, [64] saving time for patients and clinicians.

Currently, its services are either classed as:

- 'Core Services' because the NHS account has a direct role in the delivery of the service (for example, GP system services, which links to the IT system used by GP surgeries).[65]

- 'Platform Services' because logging in to your NHS account lets you access the service, but the service itself is provided outside the NHS account. [66] For example, Symptom Check is provided by NHS 111 Online.

However, during the pandemic, in 2020, many GPs suspended online booking of face-to-face appointments through the App in favour of patient triage, on the advice of the NHSE. This shows how the App's functionality is dependent on other parts of the system, making joined-up working across the system even more critical for the NHS App.

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[57] From the NHSBT team correspondence.

[58] From the NHSBT team correspondence.

[59] From the NHSBT team correspondence.

[60] NHS England. NHS App begins public rollout "https://www.england.nhs.uk/2019/01/nhs-app-begins-public-rollout/" and from comments from NHS App team member

[61] From NHSD team.

[62] As of end of May 2022. Data from NHS App team.

[63] As of end of May 2022. Data from NHS App team.

[64] As of end of May 2022. Data from NHS App team.

[65] "NHS account terms of use - Version 3.6 - 5 April 2022." NHS, 25 May 2022, https://www.nhs.uk/nhs-app/nhs-app-legal-and-cookies/nhs-app-terms-of-use/. Accessed 1 July 2022.

[66] "NHS account terms of use - Version 3.6 - 5 April 2022." NHS, 25 May 2022, https://www.nhs.uk/nhs-app/nhs-app-legal-and-cookies/nhs-app-terms-of-use/. Accessed 1 July 2022.

Levers of success: Utilising the success of COVID Pass

The introduction of the COVID Pass has led millions of new users to the App and made it the most downloaded free iPhone app in England in 2021, with over 18 million registrations between 17th May and 31st December 2021 alone. This reflects how registrations increased for a specific service, as part of the government's wider pandemic management policy. In total, 141 million COVID Passes have been generated (this is both from use of the app and the NHS.uk website).

Levers of success: User research and community partner arrangements

The NHS App team draws on user research to make good design decisions. Users are mainly recruited through online panels - a database of thousands of people who can be invited to take part in research. [67]NHS Digital have also set up user research partner arrangements with community networks and groups, especially to reach out to seldom-listened-to groups, communities and people who are often less engaged emotionally and digitally with the NHS. [68]To enable this, the team also changed their policy to set-up partnerships to make payments to community group members for their expertise as a way to reciprocate and build more equal relationships with these communities.[69]

Challenge for team: Users are not always aware of the different services on the App

Despite over 28 million user sign-ups, only 1.8 million GP appointments have been booked and 20.3 million repeat prescriptions ordered through the NHS App since it was launched.[70] In focus groups, participants were often unaware of the App's purpose or benefits. One participant in the focus group described his reasoning around the App download and usage, which resonated with others in the group, as:

> "If I had to travel, I would [download the NHS App] for the COVID pass. But I don't want to use the space on my phone to be honest."
>
> \- participant 14 (male, Black African, 42)

Challenge for team: Dependency on other services and systems within the NHS

A challenge for the NHS App team is that many of the services supported by the App are run and managed by their respective service owners - many of whom sit outside NHS Digital. GP System Services (a core service[71] provided by the App) is linked to the IT system used by GP surgeries so patients can view parts of their GP health record, book or cancel appointments, order prescriptions and send secure messages. However, this is dependent on what is enabled and authorised by individual GP practices. A practice, for example, may choose alternative online consultation platforms that sit outside the NHS App. The NHS COVID Pass (a platform service[72]) is managed by the Department for Health and Social Care, while 'Symptom Check' (also a platform service) is provided by NHS 111 online. The App has been described to us by those working on it as a 'platform'[73] - an interface that links with other existing services and systems such as GP systems. Given these dependencies, it is currently not possible for the App team to manage and control patients' entire journey.

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[67] From NHS Digital team member comment

[68] From NHS Digital team member comment.

[69] From NHS Digital team member comment.

[70] Data from NHS Digital team

[71] A 'Core Service' is where the NHS Account has a direct role in the delivery of the service. Source: https://www.nhs.uk/nhs-app/nhs-app-legal-and-cookies/nhs-app-terms-of-use/

[62] A 'Platform Service' is where logging into your NHS Account lets you access the service, but the service itself is provided outside the NHS Account. Source: https://www.nhs.uk/nhs-app/nhs-app-legal-and-cookies/nhs-app-terms-of-use/

[73] In a feedback conversation with an NHS App team member

Challenge for team: Lack of linked quantitative data

As described above, the NHS App was originally commissioned by NHS England to be primarily a data processor.[74] User data, including demographic and healthcare data is collected by primary care teams and stored locally in the GP systems. This data, as well as other data input from users, remain with their primary care provider in local GP practices and commissioning groups. According to the NHS App Direction and technical definition document (2018), 'in most scenarios data is pulled from the 3rd Party GP System Supplier's databases and displayed to the Citizen. Some data is stored in the transient Session Cache and in the persisted Audit store - NHS Number. Data necessary for the application to function, is only maintained for the length of a user session'.[75]

While the approach has clear benefits, it means the NHS App team do not have access to live data needed to create an understanding of App usage by ethnicity. As a consequence, the App design team is unable to see the real time impact of their work to improve on it - whether that is to understand how app download and usage is different for people from different ethnic backgrounds or with different health conditions, or to see whether app usage directly improves outcomes such as the patient's ability to see a GP.

Challenge for team: Lack of feedback from local GP practices and commissioning groups

There are examples of NHS Digital teams working with local GP practices and commissioning groups to identify local issues and support GPs to address them through digital. One example is engagement with Sherwood Forest Trust to host workshops with different representatives from minority communities to better understand the value of the apps and encourage people to sign up. However, initiatives like these are the exception and not the norm, and we heard from some NHS App team members that they did not get sufficient feedback or engagement with GPs and local GP practices and commissioning groups who are the primary point of contact with patients.

Challenge for team: Lack of clear and measurable KPIs

Lastly, a challenge for the NHS Digital team (as well as the entire healthcare system) is the lack of clear measurable KPIs when it comes to reducing ethnic health inequality. The public focus of the app means all features of the app are designed for, and aimed to be tested with users that are representative of the nation's population. This makes it challenging for teams to know how or where to prioritise efforts because the app does not have a clear remit to focus on the specific needs of different population groups, nor to reduce inequalities in health outcomes (unlike NHSBT).

To truly tackle ethnic health inequalities, making data open and accessible needs to be a cross-NHS priority. We will return to this topic in more detail in section 6, *Recommendations for data to hold the NHS accountable for reducing health inequality.*

4.3. A vision for a future generation of apps to reduce ethnic health inequality

Improving accessibility and usability of the apps through user-centred design methods and delivering patient outcomes are important areas of focus for App teams today. However, without timely

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[74] NHS Digital. "Establishment of information systems for NHS services: NHS App Directions 2018." NHS Digital, 27 09 2018, https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/nhs-england-directions/establishment-of-information-systems-for-nhs-services-nhs-app-directions-2018. Accessed 1 July 2022.

[75] NHS Digital. "Establishment of information systems for NHS services: NHS App Directions 2018." NHS Digital, 27 09 2018, https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/nhs-england-directions/establishment-of-information-systems-for-nhs-services-nhs-app-directions-2018. Accessed 1 July 2022.

quantitative data, it is difficult for teams to understand the impact of their efforts across different demographics in order that design decisions can be assessed, improved, or amplified to reduce inequality. The challenge of not having granular data on ethnicity and health outcomes results in teams having limited knowledge of how their work is contributing to or worsening inequality. This is particularly challenging for the NHS App team, where accessing and using data based on the usage of the App falls outside the team's remit. As apps make existing processes more efficient, digitalisation runs the risk of further benefiting existing users and exacerbating any inherent inequality in health outcomes for those seldom heard.

In the table below, we have provided some suggested actions for how digital apps could evolve over time to, firstly, mitigate the unintentional consequences of digitalisation; and secondly, start to identify more upstream opportunities for apps to intentionally target inequality and create solutions in this space.

	Current actions	Near term actions	Long term actions
Function of apps and digital services	Apps automate existing processes - e.g. booking appointments.	Apps retain existing functions and remits.	New apps or digital services should question biases in ways of working and deliver new approaches that target areas of pressing inequality.
Design and data processes	Following best practices to make the app usable and accessible for everyone, relying on general accessibility guidelines and small sample research without clear impact data. Creating partnerships with communities on the ground to ensure wider reach, yet without data to shape targeted approaches.	Use linked data to understand the consequence of the app on health inequality in order to identify emerging problems. Target design research to understanding barriers preventing ethnic minority communities from benefiting from the app, and prioritise these solutions in the backlog.	Use data and research to scan the horizon and uncover areas where inequality is most pressing, in order to identify new purposes and functions for digital services.
Outcome of digitalisation on ethnic health inequality	As apps make existing processes more efficient, digitalisation runs the **risk of further benefiting existing users and exacerbating any inherent inequality in health outcomes for those seldom heard.**	**Teams are enabled to be more conscious of their own impact**, and how they mitigate the potential impact digitalisation might have on furthering health inequality.	Digital becomes **a force to actively reduce ethnic inequality in healthcare.** New digital experiences are formed that particularly empower Black and minority ethnic communities, addressing structural barriers while building trust.

4.4. Long term commitment is needed to enable a future generation of apps

Today, digital teams are required to work in agile sprints and move forward at a fast pace, quickly iterating product solutions based on delivery prioritisation. [76]While this approach works well on large programmes by breaking tasks into manageable parts to ensure efficient delivery, working to address systemic inequalities requires a different model. Rather than being driven by delivery alone, teams would need to spend time building relationships and take a longer view towards creating interventions that look to purposefully untangle a complex and legacy driven, institutional phenomenon.

In order to proactively identify how apps can be a force to reduce inequality, the NHS must do the difficult work of unlocking data and prioritising design solutions that will look to dismantle ethnic inequalities. The ethical and moral obligation to do this is clear, but it will require political commitment to take action across the organisation. This entails:

- Giving **design and research teams** the remit to dig deeper into the root causes of health inequality so that they can identify new opportunities for digital and influence for service owners.
- Unblocking barriers to enforcing **ethical open data sharing** within the NHS to improve data quality and linkage between digital, demographic, and health data.
- A willingness to **challenge internal assumptions, biases and old ways of working**, along with leading on organisational transformation to achieve clear outcomes.

In the following sections we draw on focus group research with communities and organisational interviews to deliver early provocations on how digital, data and organisational design can help shift the NHS to boldly deliver on this vision.

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[76] Based on interviews with the App teams

5. Recommendations for design to address inequality and rebuild trust

In this section, we highlight opportunities for design and research activities undertaken by digital teams to shape more equitable services.

5.1. Design can help identify new opportunities for digital

As stated in section 4.4, the current remit of the NHS apps are not only limiting but also risk reproducing and exacerbating the status quo through a lack of equitable investment. Design needs to start with challenging existing assumptions around trust and identifying new opportunities to serve diverse communities, particularly communities who are often neglected and marginalised. This type of foundational, horizon-scanning research needs to be conducted periodically, with diverse communities, and complemented with quantitative data and evidence.

We conducted four focus groups with a total of 16 participants, where we spoke with Black African, Black Caribbean, Pakistani and Bangladeshi participants in order to understand their experiences and perspectives on the NHS and its services, including usage of NHS apps and data sharing. The insights from these sessions were synthesised into three opportunity areas for digital apps. These were:

Opportunity A. How might digital apps strengthen and improve GPs' relationship with patients?

Through the focus groups, we learnt that a key pain point for ethnic minority communities is their inability to reach and speak to a GP. GP practices have a unique and important role in the English health system. Based in local communities, GP practices are a primary point of contact for patients and the point from which they navigate the complexity of the NHS to access further services.

According to the focus group attendees, for ethnic minority communities who have historically experienced discrimination in health services, having a trusting relationship with their GP and knowing that the GP "*has their back*[77]" is even more important in making people feel safe and taken care of. However, during the pandemic, with total patient triage becoming NHSE recommended pandemic advice[78], many focus group participants felt that they experienced longer wait times. In focus groups, we heard how people felt that it was virtually impossible to get an appointment in the last two years. At a time when people of minority ethnic communities were disproportionately affected with severe COVID-19 symptoms, not being able to get direct advice or support from their primary care provider contributed to an erosion of trust, and made communities feel unsafe.

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[77] Focus group participant

[78] NHS England. Coronavirus » Advice on how to establish a remote 'total triage' model in general practice using online consultations "https://www.england.nhs.uk/coronavirus/documents/advice-on-how-to-establish-a-remote-total-triage-model-in-general-practice-using-online-consultations/" Accessed September 2022

One participant's experience with getting support for long COVID summarised this as:

> "Now they said you have long-term COVID effects, you need to get a CT scan but I can't get that done. There's a backlog of thousands of people who are vulnerable. The likelihood of me getting a CT scan is so low, so I've had to learn to self manage. I can't get through to the doctor. I feel like I'm at the point where I have to lie in order for people to say, yeah we need to speak to the person. I feel like that's what I need to do now. If you go in subtle, you won't get anything. You have to exaggerate."
>
> - Participant 5 (male, Black Caribbean, 49)

These difficulties in accessing GPs resulted in people self-managing their care. Some of the focus group attendees moved towards self-medication, holistic natural remedies. Immigrants, who had family ties abroad, told us that it was easier to get prescription medicine including antibiotics, sent over from other countries. Other than friends or family, people turned to the internet and social media for sources of information. For many, the NHS no longer felt like the most trusted source of healthcare information and advice. This included the advice people could access on the NHS website.

Given the importance of GPs as a primary point of contact based in local communities, our team proposes that digital apps could have had an additional role in helping strengthen and improve this relationship. An example of this could be done by giving people reassurances and follow up after their initial appointment. Another approach could be providing people with greater continuity, by enabling them to connect with the same clinician or staff member at their practice. We think that there could also be a role for apps to widen access to clinical and preventative support in different neighbourhoods and locations by working together with other local medical professions such as pharmacies.

Case study:
Kry - Swedish telemedicine platform pairing patients with one family doctor.

Telemedicine has been prominent in Sweden for many years and its role in primary care has been cemented through the pandemic. Telemedicine is managed and promoted by the Swedish eHealth agency.[79] In Sweden, Kry (the largest telemedicine platform) has since 2015, conducted over 3.7 million patient meetings. [80]Unlike in England, in Sweden, Kry users are paired with one family doctor – ensuring everyone in the family sees the same doctor every time and gets a personal contact.

Opportunity B. How might digital apps be designed for use by community groups and extended families?

Mosques, churches, extended families – these local and familial networks play an important role for Britain's minority ethnic communities, offering valuable social, emotional, and cultural security. From focus groups, we learnt how when it comes to healthcare, people often seek support from and are more willing to offer it to people within their own ethnic groups. Research has shown the importance of grassroots community to bring nuance in communications, enable trust and confidence[81]. NHSBT are already aware that minority ethnic communities are more likely to give blood donations when the call to action comes from someone they know, a religious leader, or someone in their community group. The organisation is investing in designing outreach and marketing campaigns targeted towards these communities. [82]However, current digital tools do not support people creating a call to action that could be customised for their own communities, which could enable more targeted and effective engagement.

[79] E-hälsomyndigheten. "Welcome to the Swedish eHealth Agency." E-hälsomyndigheten, 22 March 2016, https://www.ehalsomyndigheten.se/other-languages/english/. Accessed 6 May 2022.

[80] Kry International AB. "This is Kry." Kry, https://www.kry.se/en/about/. Accessed 6 May 2022.

[81] NHS Race and Health Observatory. Ethnic Inequalities in Healthcare: A Rapid Evidence Review

[82] From NHSBT team interview.

We heard from our focus group attendees that it is often commonplace for people from minority ethnic backgrounds to share and handle digital and health information for family members - especially older relatives who might be less comfortable with digital or English capability. Participant 7 (male, Asian Indian, 29) spoke about his relative's experience with the language barriers:

> "My grandma can't speak English well. When she was in hospital, we were only allowed a one hour slot to visit her - explaining about meals, if she wants a shower, etc. No staff spoke Hindi….so it was hard for her to get what she needed the rest of the time."

We also heard examples of instances where people shared one mobile phone device across multiple family members.

Designers of digital tools often assume that people own an individual mobile phone and are accessing services for themselves, rather than others. There is an opportunity for digital services to recognise the more communal ways in which many minority ethnic families and communities operate and design for these so that there is support and informed consent built in. An example of this is the NHS App video campaign that looked to improve people's access to health information and support in communities where English was not the first language in north east London. This local campaign looked to promote the NHS App in Somali, Romanian, and Bengali. While the App features highlighted in the videos were of particular interest and benefit to older users, the campaign was aimed at younger family members who might then support older relatives to download, set up an NHS login and use the NHS App.[83]

Case study:
The American Red Cross App

Not just a functional appointment-booking app, the American Red Cross App taps into people's desire to know how their blood donation benefits their local community. Donors can track their blood and see the hospital that it ends up at and when it has arrived. Being able to obtain this level of detail encourages donors to keep going as they can appreciate the lives it is going to save in their local area. It also gamifies blood donation by allowing people to form teams, challenge others to see who can donate the most and earn badges.[84] Lastly, the app provides alerts to let people know when their specific blood type is needed, making blood giving personal and making the community support link clear.

Opportunity C. How might digital apps pull people in through trusted content with a personal face?

We heard from focus group participants how throughout the COVID-19 pandemic, faced with a worrying public health crisis and unable to speak to their primary care provider, the internet grew in importance as a source of trusted information and advice for people. Participants talked about how they felt bombarded with health information and official messaging but had a hard time distinguishing whether decisions (such as a reversal of self-isolation policies) came from the NHS, Public Health England, or the government.

The volume and intensity of public messaging, the inconsistency and changes in policy, as well as the alarming tone often amplified by the media, fatigued people and made them sceptical of official health messaging as they could not distinguish between the clinical voice and political motivation.

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[83] NHS North East London. NHS App video campaign supports communities in north east London "https://northeastlondonccg.nhs.uk/news/nhs-app-video-campaign-supports-communities-in-north-east-london/#:~:text=The%20languages%20chosen%20by%20the,to%20health%20information%20and%20support." Accessed June 2022

[84] 3 Sided Cube. "SAVING LIVES WITH THE WORLD'S FIRST BLOOD TRACKING APP." 3 Sided Cube, https://3sidedcube.com/projects/saving-lives-with-the-worlds-first-blood-tracking-app/. Accessed 6 May 2022.

People looked for reassurances via existing or trusted relationships online, with friends, family, local community groups or religious leaders. As a result of this decreased trust, when looking for health information online, the NHS website and App were not the number one source for all people[85] .

Younger generations especially navigated towards video content on YouTube or social media channels, where they could engage with virtual physicians who sometimes shared their ethnic background. As participant 3 (female, Black British, 31) from the first focus group said:

> "On twitter, you create your own echo chamber. Someone in there will be a doctor or nurse… the same age range, gender, etc. [as you]. They'll give different advice to the NHS sometimes. I deliberately follow doctors on twitter and trust them more than a random text from the NHS."

NHS and NHSBT could further explore different content formats, styles and even publishing platforms and approaches that could be more accessible for different audiences.

Case study:
Cervical screening campaigns

Cervical screening campaigns have prominently featured on the NHSs social media channels. As part of this, the NHSofficial Instagram account partnered with Gynaecology Doctor Dr. Anita Mitra MBChB PhD MrCOG, who goes by the Instagram Handle 'gynaegeek' and has 153K subscribers; and GP Dr Zoe Williams whose instagram 'drzoewilliams' has 117K followers; to create social media content on cervical screening awareness

The above are three areas of opportunities and examples that showcase a different approach to digital, while identifying new ways to add value for people from ethnic minority communities, based on insights from the focus groups. These opportunities also show how working equitably towards reducing health inequalities, can also surface latent and often unmet needs, particularly from areas of the population that have been historically marginalised.

5.2. Build on existing NHS design principles to shape a more explicit approach to addressing ethnic health disparities

The NHS Design principles[86] from the NHS digital service manual provide a solid foundation for digital teams to set up services rapidly and consistently. These are well regarded principles that have led the way in creating consistent design standards for diverse NHS services. They played a particularly important role in helping NHS Digital to nimbly respond to rapid policy changes during the pandemic.[87]However, these principles were drafted well before the pandemic, when public expectations for digital were different to what they are now. We also heard from an NHSD team member about how

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[85] OECD. Transparency, communication and trust: The role of public communication in responding to the wave of disinformation about the new Coronavirus "https://www.oecd.org/coronavirus/policy-responses/transparency-communication-and-trust-the-role-of-public-communication-in-responding-to-the-wave-of-disinformation-about-the-new-coronavirus-bef7ad6e/" Accessed September 2022

[86] NHS Digital. "NHS Design principles." NHS digital service manual, 08 2018, https://service-manual.nhs.uk/design-system/design-principles. Accessed 1 July 2022.

[87] Ha, Lucy. "Building great digital services during a crisis." NHS Digital, 22 December 2021, https://digital.nhs.uk/blog/transformation-blog/2020/building-great-digital-services-in-a-crisis. Accessed 1 July 2022.

these design principles were initially created with a less diverse sample of users. [88]These principles should be reviewed to reflect a more ambitious NHS commitment to move towards more equitable outcomes in healthcare. A revised set of design principles will ensure future design teams are putting issues of equality front and centre in their design considerations.

Design should strive for equity in addition to inclusivity

Guided by the third NHS design principle, currently titled 'Be inclusive', both NHSBT and NHS App teams are highly invested in efforts to increase accessibility and improve the usability of the two apps. However, in order for the NHS to cater for everyone equally, there also needs to be a more explicit emphasis on designing for equity. [89]This means the NHS should recognise that each person or group has different circumstances and allocate the proportionate resources and opportunities needed to achieve an equal outcome for everyone.

Designing for equity might mean reaching out more or providing specific services to those who have been historically marginalised, even those who don't usually engage with the NHS. For example, language is an area that can be a key barrier for many migrants who are less confident English speakers, and who often cannot access healthcare services independently. Equitable digital design should ensure that services can be accessed by individuals who do not speak English. The COVID-19 app was a success story in its ability to simultaneously release and then iterate in 12 languages at the same time.[90]

Case study:
NHS digital service manual

NHS Digital have recently updated their digital service manual to reflect a more inclusive style, including when and how to refer to ethnicity, religion or nationality, making written content and imagery of skin symptoms representative of people with various skin tones. [91]The content design update shows how the NHS Digital team is already working on small but institutional changes that reflect a broader commitment to equality.

Design should engage with political, social, and cultural context

The fourth NHS design principle, 'design for context', is typically interpreted as meaning that designers need to understand the end-to-end experience that patients have with a healthcare service, beyond any single digital touchpoint.

However, while patient-centric journeys are critical to shape joined-up experiences and services, there is still a lack of guidance around understanding the foundational and structural contexts that shape expectations and behaviours for ethnic minority patients. Often the lived experiences of encountering structural racism and unequal power dynamics create deep mistrust between patients, their primary care professionals and the NHS.

In order to truly create equitable relationships with minority ethnic communities, we think that digital and design teams working in healthcare also need to engage with the social, political, and historical context that communities are in.

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[88] From NHSD team interview

[89] Online Public Health. Equity vs. Equality: What's the Difference? | Online Public Health "https://onlinepublichealth.gwu.edu/resources/equity-vs-equality/"

[90] From a former team member working on COVID-19 app.

[91] NHS digital service manual. Content style guide - - - Inclusive content "https://service-manual.nhs.uk/content/inclusive-content"

Case study:
A.T. Beacon Project

An example of this is the A.T. Beacon Project. The Project currently works with local groups and organisations across Lambeth, Lewisham, and Southwark and acts as a bridge between the NHS and communities by developing strategic partnerships with faith leaders and local GP practices, local carers' hubs, and voluntary organisations, promoting a culture of empowerment and co-creation. By working alongside communities, their families, and peers, the project creates safe spaces (Beacon Hubs) where people can gain access to trusted voices and sources on matters concerning health, wellbeing and vaccine confidence. These take place often in partnership with local community groups in focal areas such as churches and community centres or in virtual spaces. Initiatives like this - already sponsored and supported by the NHS - demonstrate feasible examples of how local partnerships can be scaled.

Design should acknowledge and rebuild broken trust

The fifth design principle 'Design for trust' is particularly significant to this report. Throughout the research, we heard about the importance of trust when it comes to engaging Black and minority ethnic communities with healthcare services. We also heard concerns from NHS teams, experts, and community members about the lack of trust that currently exists between the NHS and ethnic minority communities. We heard how the pandemic had widened this lack of trust. These sentiments were echoed across the board from interviews with NHS staff, experts, patients and community groups.

The NHSBT App team have conducted research that shows how the lack of trust in health and care processes created barriers that prevent minority ethnic communities from proactively engaging with the service and donating blood. Internal efforts also proved that rebuilding trust with local communities was one of the most important ways to increase engagement. [92]This led to schemes like the Community Investment Scheme that funds community and faith organisations to drive awareness, understanding and behaviour change. [93]The NHS Digital team has also been looking at addressing health inequalities by understanding different barriers that people face such as trust and language, by putting strategies in place to research more inclusively.[94]

Despite this, the fifth design principle is currently described as 'People trust the NHS. Take care not to jeopardise that. Design things that are reliable and secure'. Rather than begin from the assumption that all people trust the NHS, we recommend reviewing and reshaping the principle to reflect the urgent need to rebuild trust with communities, especially if they are ethnic minority groups, and acknowledge the complex history and relationships that people have with the NHS to start rebuilding trust that is broken.

Building nuance into NHS design principles for a checklist for a future generation of Apps

Using the current NHS Design Principles as a starting point, we have created an updated checklist that builds in additional nuances for teams actively looking to reduce ethnic disparities. These principles can be found at the end of this report (after the Conclusion) and are a handy guide for any team working in digital healthcare who want their work to be more ambitious and proactive when it comes to reducing inequality and driving equity.

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[92] Interview with NHSBT digital team, Feb 2022.

[93] 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.

[94] Interview with NHS Digital team, Apr 2022.

5.3. Summary of recommendations for design

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:

3. 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:

4. 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.

6. Recommendations for data to hold the NHS accountable for reducing health inequality

As mentioned in section 4.1, lack of quality data is one of the largest barriers to addressing ethnic health inequality, not just for the two app teams but for the wider NHS. Quantitative data is important in this area of study because often individuals can only speak of their subjective individual experience, and don't have a frame of reference to compare it to members of other ethnic groups. Data that links evidence and subjective experience to health outcomes is key to identifying health inequalities and its possible causes, and to plan for targeted interventions.

It is challenging to draw robust conclusions on the impact of discrimination on health based on the data that exists currently. This was a key finding from the NHS RHO's Rapid Evidence Review on Ethnic Inequalities in Healthcare (published February 2022). The review identified qualitative evidence that women from minority ethnic backgrounds felt that they were underserved or discriminated against, throughout their maternity care. When an attempt was made to understand quantitative data available on ethnic inequalities in accessing or receiving particular NHS services or treatments (e.g. timely antenatal booking appointments, Caesarean delivery or breastfeeding support), the data was found to be patchy and inconsistent. [95]This made it challenging to draw correlations or causation between subjective experience and health outcomes.

In this section, we will focus on two components of this challenge - inconsistent ethnicity coding and difficulties with internal data sharing.

6.1. Inconsistent ethnicity coding is a challenge across the NHS

Ethnicity is a complex, multidimensional concept, often defined by features such as a shared history, common cultural traditions, a common geographical origin, language and literature. It is therefore, a highly subjective classification that an individual is usually required to articulate within a simple data item structure. [96]

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[95] Kapadia, Dharmi, et al. "Ethnic Inequalities in Healthcare: A Rapid Evidence Review." NHS Race and Health Observatory, February 2022, https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf. Accessed 6 May 2022.

[96] Raleigh, Veena, et al. "Ethnicity coding in health records letter." The King's Fund, 12 October 2020, https://www.kingsfund.org.uk/sites/default/files/2021-01/NHSE-letter-ethnicity-coding-health-records-oct2020.pdf. Accessed 6 May 2022.

Ethnic record keeping/monitoring has been undertaken for the past 20 years, but has often been carried out in an ad-hoc manner, resulting in incomplete and unvalidated data. [97]The proportion of records coded as ‘other’, ‘other Asian’, ‘other Black’ and ‘other White’ is higher in health records than in other sources, indicating miscoding. Over-coding of ‘Other’ groups can have the consequence that rates for other ethnic minority groups are likely to be underestimated. Furthermore, categories such as ‘Black’ or ‘South Asian’ bring together groups with different influences in terms of culture, religion and lived experiences that often don’t capture the nuances between the different ethnic subgroups. As one participant in the shareback session asked, “My ex-wife is Asian and my daughter is mixed- the ‘other’ category doesn’t fit. Is there work being done to expand these choices?”. It is difficult for patients to give the right data, when categories for data capture do not reflect their identities.

Nuffield Health Trust supported the NHS Race and Health Observatory to conduct a thorough review of ethnicity coding in English health service datasets (excluding GP records). Their analysis of the quality of ethnicity coding in hospital datasets found that the proportion of health records containing the patient’s ethnicity code was high, with 87% of the 17 million inpatient spells having a valid ethnic group recorded in 2019/20. [98]However, data often had quality problems including incomplete coding and inconsistent use of codes; an excessive and growing proportion of patients having ethnicity recorded as ‘not known’, ‘not stated’ or ‘other’ which impedes reliable analyses of ethnic differences; and systematic biases in data quality. Data quality was worse in London, in adults of working age, and for patients with short hospital stays. Importantly, data quality problems affected records for minority ethnic patients disproportionately.

When it comes to GP data, prior to the pandemic it was thought that ethnicity was recorded in around 60-70% of GP records. [99]However, from January 2021 GPs are contractually obliged to record patients’ ethnicity in their records where patients are happy to share it. [100]In certain clinical settings, ethnicity is sometimes incorrectly assigned by staff. This may be because staff are under time pressure, unaware of the correct procedure, or patients’ lack capacity to fill the form themselves.[101]

In its *Rapid Evidence Review*, the NHS RHO identified poor ethnicity data recording as well as lack of infrastructure to link data across as the two of the largest barriers preventing more granular knowledge and solutions across the NHS. This sentiment was echoed by the Health Foundation’s Marmot review (2020) - which calls for building more effective whole system data sets and improving data for ethnicity.[101]

Increasing compliance, consistency, and accuracy of patient ethnicity coding needs to be one of the highest priorities across the NHS. The accountability for this needs to be clarified so that it sits with the appropriate organisations, ensuring accurate data collection at all levels. More work also needs to be done to understand existing challenges and barriers that doctors, nurses, staff and patients have with inputting accurate data, to inform updated guidance and streamline the process. We recommend that the The Health Inequalities Improvement Programme at NHS England and NHS Digital work with the NHS Race and Health Observatory to conduct further research to update the guidelines and process for ethnicity coding in the NHS.

[97] Iqbal, Gulnaz, et al. “Improving ethnicity data collection for health statistics in the UK.” Sheffield Hallam University Research Archive, Diversity in Health and Care 2009, 2009 Radcliffe Publishing, https://shura.shu.ac.uk/5567/1/Gumber%20Improving-ethnicity-data-collection-for-health-statistics-in-the-uk.pdf. Accessed 6 May 2022.

[98] Scobie, Sarah, et al. “Ethnicity coding in English health service datasets.” The Nuffield Trust, 7 June 2021, https://www.nuffieldtrust.org.uk/research/ethnicity-coding-in-english-health-service-datasets. Accessed 6 May 2022.

[99] Kituno, Nick. “NHS England agrees to collect ethnicity data seven weeks after COVID vaccinations began.” Health Service Journal, 26 January 2021, https://www.hsj.co.uk/primary-care/nhs-england-agrees-to-collect-ethnicity-data-seven-weeks-after-COVID-vaccinations-began/7029378.article. Accessed 6 May 2022.

[100] Wilkinson, Emma. “GPs now contractually obliged to record patient ethnicity.” PulseToday, 28 January 2021, https://www.pulsetoday.co.uk/news/contract/gps-now-contractually-obliged-to-record-patient-ethnicity/. Accessed 6 May 2022.

[102] Raleigh, Veena, et al. “Ethnicity coding in health records letter.” The King’s Fund, 12 October 2020, https://www.kingsfund.org.uk/sites/default/files/2021-01/NHSE-letter-ethnicity-coding-health-records-oct2020.pdf. Accessed 6 May 2022.

6.2. Data sharing lacks maturity and is impacted by past mistakes

Data is not open and linked across the NHS

Even where individual datasets exist, it is not always possible to anonymise data, or to safely and ethically share it within the NHS for research purposes. NHS RHO's *Rapid Evidence Review*[103] has identified that data linkage across different datasets, across primary care settings and across regional and national levels is a key barrier to having an overview of existing inequality in health outcomes for evidence-based decision making.

Experts are concerned about NHS track record on data security

Personal data collection and sharing, particularly when it is about health and medical records, is a highly sensitive topic and needs to be carried out with the utmost care, diligence, scrutiny. Today, data is collected and handled at all levels of the NHS. Despite some existing guidelines, there has not always been consistent enforcement, adequate training, or infrastructure to support and guide staff across different levels of the organisation. As a result, a number of missteps have been made in the past leading to the NHS facing intense public scrutiny. A notable incident was in 2015, when health records of patients of the Royal Free London Trust were shared with Google DeepMind, in breach of the Data Protection Act 1998 (the then applicable data protection legislation).[104] These data breaches also occasionally occur either as a result of human (staff) error or poor internal security systems coupled with intentional hacking attempts,[106] putting millions of patients at risk and making the public question NHS capacity to securely handle and process data. This lack of faith means that campaigners, experts and some members of the public are rightfully cautious about NHS attempts to expand the scope of data collection and analytics[107]. The launch of General Practice Data for Planning and Research (GPDPR) is expected to develop a more secure and consistent way to collect data from GP records. However, the programme has been criticised for not sufficiently engaging with the public. It has been postponed to give more time to listen, understand, and engage with GPs, medical professionals and members of the public.[108]

Community members were open to sharing data to receive better care

An online survey of the UK YouGov panel found that there were no ethnic inequalities in how comfortable people were in sharing personal data via COVID-19 contact tracing app, either with the government or industry-led tracing apps.[109]

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[103] Kapadia, D., Zhang, J., Salway, S., Nazroo, J., Booth, A., Villarroel-Williams, N., Bécares, L., & NHS Race and Health Observatory. (2022, February). Ethnic Inequalities in Healthcare: A Rapid Evidence Review. NHS Race and Health Observatory. Retrieved May 6, 2022, from??????

[104] BBC.co.uk "Google DeepMind NHS app test broke UK privacy law." BBC, 3 July 2017, https://www.bbc.co.uk/news/technology-40483202. Accessed 6 May 2022.

[105] Glover, Claudia. "NHS patient data breach could have big implications." Tech Monitor, 21 February 2022, https://techmonitor.ai/policy/privacy-and-data-protection/nhs-patient-data-breach-psl. Accessed 6 May 2022.

[106] Heather, Ben. "Exclusive: One in five trusts did not make critical security updates before cyberattack." Health Service Journal, 17 July 2017, https://www.hsj.co.uk/technology-and-innovation/exclusive-one-in-five-trusts-did-not-make-critical-security-updates-before-cyberattack/7020083.article. Accessed 6 May 2022.

[107] 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.

Edwards, James Castro. "Not without consent: Legal risks for NHS data sharing." Pharma Times, October 2021, https://www.pharmatimes.com/magazine/2021/october_2021/not_without_consent_legal_risks_for_nhs_data_sharing. Accessed 1 July 2022.

[108] General Practice Data for Planning and Research (GPDPR)

[109] Kapadia, D., Zhang, J., Salway, S., Nazroo, J., Booth, A., Villarroel-Williams, N., Bécares, L., & NHS Race and Health Observatory. (2022, February). Ethnic Inequalities in Healthcare: A Rapid Evidence Review. NHS Race and Health Observatory. Retrieved May 6, 2022, from

In our focus groups with Black African, Black Caribbean, Pakistani and Bangladeshi community members, participants assumed that their data was already being shared with the NHS. Participants spoke about how they were often asked to repeat the same information when seeing different care practitioners - but saw no benefit in return. For example, some participants felt that despite repeatedly giving information about their conditions, GPs were unaware of their health history and did not offer follow ups to known conditions. Most participants said that they would be happy for the NHS to share and use data more to realise tangible health benefits for individuals and their community. Participant 12 (male, Black British, 34) from the fourth focus group said: "One day god forbid if I have an emergency, [the NHS holding data on me] is ok because they are using that to help me as an individual."

Other participants mentioned that they would appreciate knowing about the risk factors their ethnic community are particularly susceptible to, and being proactively supported to manage these risks. For them, this would be a very positive use of ethnicity data. For example, participant 5 (male, Black Caribbean, 49) stated, "My dad had prostate cancer… He was regularly seeing a doctor and doing blood tests but they didn't diagnose him. He was old, Black, it's like… why didn't you scan for it? It's a known risk for Black people."

With more people using digital channels more often - whether that be through apps or websites, many people from the focus groups accepted sharing their data with the services they use. Most participants had their own mental models to assess whether they trust the service enough or whether there is important reason to share data. For example, participant 5 (male, Black Caribbean, 49) stated that he "would input personal information to get a bank account, but not just to receive information on car purchasing". Overall, participants saw that getting health care and preventative care was an important need, and most were comfortable sharing their data with the NHS.

However, many participants emphasised that data collection should be voluntary and should benefit the individual directly. Many participants drew a firm, clear line on how data should not be shared with the government or any third party without clear informed consent. As participant 12 (male, Black British, 34) notes: "Anything beyond there [that benefits the individual] is different. It should be voluntary." Participant 1 (female, Black British, 29) spoke of their mistrust with data being shared with the government: "Years ago when I was on benefits, I was living in fear of saying the wrong thing - I feel it is all one big system, and [I was] not having any insight around what's going on with my information".

The sessions show that there is value in clearly explaining boundaries around data sharing - whether that is to support outcomes for individuals, communities, or broader research. Key here is explicitly defining and communicating hard boundaries across different organisations and purposes. An example of this could be stating clearly that individual identifiable data will not be shared with the government departments for any purposes.

It is important that the NHS engages with the public upfront and explores public expectations and ethics around data, 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 stream of work that informs NHS's wider data strategy.

6.3. To unlock opportunities from data, the NHS needs to establish itself as a trusted data holder and processor

It is clear that having access to data across the NHS for research and design purposes would be invaluable not just for reducing ethnic health inequality, but for improving health outcomes in general. The Black, Asian, and ethnic community members we spoke to saw the potential for data-driven services to address the sharp pain points they had been experiencing since the pandemic: patient triage systems where there was a slower follow up from NHS primary services, reduction and often difficulty in spending time with GPs; and lack of preventative care targeted towards conditions known to impact ethnic minority groups. Here, ethnic minority community members were open to more digitised services and benefits that mitigated these and provided value for them.

However, past issues around the handling and processing of patient data has led to some scepticism, especially from experts and community groups. Revamping the NHSs approach to data collection is urgent, necessary. Change at this scale needs to be done with the right levels of engagement with the public and healthcare professionals, as the NHS has learnt through its first attempts launching the General Practice Data for Planning and Research (GPDPR)[110]. Rather than reinventing the wheel each time, the NHS should build on, adapt, and enforce existing industry best practices (such as Open Data Institute's Data Ethics Canvas) to make ethical data decisions simple and straightforward for each and every single NHS staff member. This requires upskilling staff on data literacy - including how to use, process, collect and communicate to the public about data.

Data sharing with third parties is a sticking point for the public and civil society. Given the number of external and private contractors that the NHS relies on (the NHS spent £271 million on outsourcing services in 2018/19 alone[111]), it is not possible for the NHS to not share data with the private sector. [112]However, more can be done to set out and communicate clear guidelines and boundaries to the public, on how the NHS will share data externally. As part of this process, there is also an opportunity for NHS Digital to partner with NHS RHO for further research, engagement and co-design activities with Black and minority ethnic communities on data privacy guidelines.

As structural racism and bias is systemic, the responsibility to process, analyse, and use data to counter bias should not necessarily only be held centrally. Empowered with the right technological support and data literacy, local GP practices and commissioning groups, for instance, can also use data to examine their own practices. This can be done by reviewing time spent and rates of referral for patients of different ethnic minority groups as a way for GPs to start identifying and reducing bias in their own practice.

Accountability is a key challenge when it comes to holding different levels of NHS staff responsible for not only collecting better data, but also adhering to ethical standards for processing, storing, as well as using data to reduce bias and improve internal processes. Given the new remit of ICSs to implement a population health platform, which focuses on the wider determinants of health and brings together local health and care services with the explicit mandate to reduce inequality, [113]it makes sense for ICSs to also hold the accountability for enforcing data standards locally.

Alongside holding data, there is also a need to invest in building data analytical capability and capacity to derive value from data. As referenced previously in the report, while NHSBT collects data, the dataset is often poorly organised and needs more processing capacity and human resource to produce trends that are usable by NHSBT teams. Thus, while there is a need for healthcare organisations to review data collection, sharing and communication practices, there is equally a need to review and build data analytical capability and capacity to truly unlock the potential opportunities offered here.

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[110] NHS Digital. "General Practice Data for Planning and Research (GPDPR)." NHS Digital, 15 March 2022, https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research. Accessed 6 May 2022.

[111] "Is the NHS being privatised?."https://www.kingsfund.org.uk/publications/articles/big-election-questions-nhs-privatised-2021#:~:text=Data%20from%20NHS%20Improvement%20shows,to%20deliver%20waiting%20times%20targets. Accessed 6 May 2022

[112] From interview with NHS Digital team

[113] NHS England. "Population Health Management: Understanding how integrated care systems are using population health management to improve health and wellbeing" https://www.england.nhs.uk/integratedcare/what-is-integrated-care/phm/

6.4. Summary of recommendations for data

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)[114]. 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.

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[114] 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.

7. Recommendations to enable diverse and integrated teams for equitable decision-making

The NHS needs to proactively invest in digital tools and approaches to reduce ethnic health inequalities. This also means investing in ways of working that break down organisational silos, enabling digital and design teams to work with others to make decisions that lead to improved and joined up health and care services, centred around the experiences of patients. Design and data teams who operate within NHS organisations need the support of national NHS leadership including leadership across organisations such as NHSBT, NHSE, and NHSD to create the right conditions to work towards equitable health outcomes. In some instances, this requires a more representative team so that teams don't just work towards inclusive services but are inclusive and diverse in themselves. In this section, we will highlight some of these broader transformations that need to happen across the NHS.

7.1. Building and empowering diverse digital teams

Digital teams need to reflect the diversity of the population and of the NHS workforce. Nearly 20% of the 1.3 million people that work in the health service are from a Black, Asian or minority ethnic background. If digital teams are committed to reducing ethnic inequality, hiring and retaining diverse team members would be a critical step. Equally, in expert interviews, we heard that having senior leaders from ethnic minority groups signals a strong commitment to reducing health disparities and gives reassurance to local community groups.

It's also important to note that racism in the workplace has been well documented inside the NHS. The 2016 NHS Workforce and Race Equality Standard (WRES) highlighted that 41% of Black and minority ethnic colleagues said that they were being bullied, harassed or abused compared to 18% of White staff. There is also evidence that the NHS recruitment process disproportionately favours White applicants, while previous research has highlighted concerns about the absence of Black and minority ethnic colleagues in senior NHS roles.[115]

Issues of structural racism in the NHS workplace are likely to impact digital teams as well, and while building diverse teams is important, nurturing and caring for the wellbeing of Black and minority ethnic colleagues is an equally important priority. Aware of these issues, the NHS is already making progress through formal initiatives such as Leadership Academy and staff-led initiatives such as Shuri Network[116], the first NHS and care network of women from minority ethnic groups in digital health. Continued investment in diverse staff and networks that support staff from minority communities is necessary to ensure that all staff are supported and empowered to understand, empathise, and make decisions that affect patients from ethnic minority communities.

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[115] NHS. "Inclusion, equality and diversity – Leadership Academy." NHS Leadership Academy, https://www.leadershipacademy.nhs.uk/resources/inclusion-equality-and-diversity/. Accessed 6 May 2022.

[116] Shuri Network. https://shurinetwork.com/

7.2. Invest in training that unpacks racism, anti-racism and inclusive practices, creating awareness and giving delivery teams shared frameworks to work from

Structural racism is complex, challenging and an emotional topic for people to understand or know how to respond to. In the workplace, those who might be unfamiliar with the topic, can appear defensive, shocked, or unsure about how to respond to the topic. Furthermore, working on mitigating or reducing structural racism can bring up emotional trauma for Black and minority ethnic colleagues. Often in the absence of organisational strategy and investment, those who have faced racism themselves often feel like they bear an outsized responsibility to explain, bring colleagues along or create spaces that create an awareness or mitigations towards addressing racism. To enable and empower digital teams and meaningfully engage and respond to structural ethnic disparities, teams must first align around a shared vocabulary, baseline knowledge and organisational mandate. Training that unpacks racism, anti-racism and inclusive practices is a good place to start this important conversation, create awareness and give delivery teams shared frameworks to work from.

7.3. Setting up metrics of success that are grounded in outcomes for ethnically diverse users

As health inequality is such a broad and complex topic, teams need clear goals to both measure success and align efforts. Key to setting up these goals is not just to make them measurable but to measure that success by grounding it in the experiences and goals of the multiple, ethnically diverse users that access and use the digital services and apps. Alongside this, digital teams should partner with stakeholders, commissioners, and other organisations to set up collective place-based goals, ensuring joined-up services in a geographic area. These goals can be linked to NHS England and Improvement's equality objectives and the wider NHS vision to create equality by delivering equitably.

7.4. Digital should be an integrated component of the healthcare journey

Digital and app teams often sit separately to wider healthcare delivery in large organisations, which reinforces a feeling of websites and apps being a separate product. This contributes to a fragmented digital experience and overall disjointed healthcare experience. The NHS Digital team bridges digital and healthcare delivery by working in an integrated way with clinical teams - however, this is not standard practice across other digital teams. In the long run, the responsibility for 'Digital' needs to go beyond the remit of creating isolated apps, websites and other tools. Digital needs to become an enabler for joined up health and care services by tying together different services and patient activities, with multidisciplinary teams organised in a structure that enables this. Teams can work with local GP practices and commissioning groups or different NHS departments to set-up patient journeys, while coaching other departments on adopting new, agile, digital mindsets and ways of working. Digital would thus become everyone's responsibility.

To do this well, there is also a need for the NHS to consider new models of service leadership and ownership for accountability and vision that gives direction while ensuring quality for end user experience and patient outcomes. Clear accountability along with multidisciplinary, collaborative ways of working will lead to more joined up experiences for patients and a better understanding of health outcomes. This would enable Digital and App teams to work closely with service owners to use data, develop and test solutions for joined up services. An example is the work done by NHSBT in 2021 towards a new service ownership model for donor experience.[117]

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[117] Based on NHSBT case studies with TPXimpact (formerly FutureGov)

7.5. Promote a culture of cross-disciplinary learning and improvement

Though there is a clear need for open, linked data across the NHS to see patterns across digital usage and clinical outcomes, the true potential of data is only realised when it is used. National NHS leadership including leadership for organisations such as NHSBT, NHSE, and NHSD need to plan for and set-up structures around cross-disciplinary learning, sharing and transparency. This includes setting up spaces for design experiments and learning to improve processes, surfacing and validating assumptions or ideas that work towards equitable health outcomes in a joined up way. This joined-up working means bringing together different functions - operational, clinical, strategy, experience, manufacturing, as well as digital and DDTS/IT (Digital, Data and Technology) leadership around shared user outcomes based goals for improvement, while creating space for iterative and learning approaches across the organisations.

7.6. Summary of recommendations

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.

Connected

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

3. 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.

Systemic

Recommendations that require a clear leadership mandate for systemic reform:

4. 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 .
5. 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.
6. NHS leadership should consider new service ownership models that enable app and digital teams to work more closely with service owners 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.

8. Conclusion

Health inequalities have been shaped by the country's political history, immigration, and wider determinants of health, such as education, employment, housing; as well as the NHS's complex structure, which collectively embed profound ethnic inequalities in health outcomes. Ethic health 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. There are many factors that contribute to inequalities outside health and even the NHS. This has an implication on how we design for healthcare services which look to reach out and support all people equally. To ensure our services reach people equally, we need to focus efforts equitably to repair trust and reach out with more support to those who have been systemically underserved in the past, thus actively reducing inequality in healthcare services.

In that respect Digital, especially apps, are not a standalone solution, but are part of a wider ecosystem of health and care services. Digital offers a set of channels that can enable a wider reach for their audience, yet these channels are adopted on the basis of trust that sits within a wider ecosystem of services. The NHS, including NHS Digital and NHSBT have an important role as a direct interface to millions of people, with the pandemic particularly revealing how more effort is needed. Digital is a critical interface that directly reaches out to users through websites and apps, with digital ways of working representing a key enabler in healthcare service delivery. **Addressing ethnic health inequality requires a comprehensive and systemic policy and NHS response, of which digital can be one powerful driving force.**

Digital teams need the remit, funding and support to dig deeper into the root causes of health inequality, to identify new design opportunities, and to challenge existing assumptions and frameworks that determine current ways of working. Teams also need to have linked data cutting across demographics, clinical outcomes, and digital behaviours to see impact of the work and to make the right changes and adjustments. It is key that the NHS engages with the public upfront and explores public expectations and ethics around data, particularly with members of Black and minority ethnic communities to co-design data policies.

As digital across the NHS and NHSBT matures and apps evolve, it is essential that the NHS, including NHSBT invest in digital transformation - including transforming tools, culture, and processes to proactively reduce inequality. Digital transformation that is joined-up and looks to work in an equitable way, can result in better health outcomes for all. **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.**

Existing initiatives such as the NHS' new inclusive content design guidelines, NHSBT's community investment scheme, A.T. Beacon Community Hubs, plans to engage the wider public around GPDPR, and the Shuri Network of women from minority ethnic groups in digital health, all collectively demonstrate that change is within reach for the wider NHS, including NHSBT and NHSD, while laying the groundwork for future transformation that ensures true equality through equity.

Principles for reducing ethnic health disparities

Below, we have provided a checklist of key considerations for any team working in digital healthcare. The list is based on current NHS Design Principles and includes details added by our team that are important to consider when looking to address ethnic disparities. The text in italics is where our teams have made suggestions to emphasise or clarify best practices when designing to reduce ethnic disparities. The original content of the NHS Design Principles, together with the additional nuances added by our team, make for an actionable list that digital design teams can apply when designing to reduce ethnic health disparities.

1. **Put people at the heart of everything you do**

   Patients, family, carers, staff *and the communities they are part of.* Design things that understand and respect people's needs. Take the time to learn about the whole person - their emotional, physical and technical needs, *their communities and their cultural, social and historical contexts.*

   Design with compassion, *and where possible start by co-designing with communities and groups that are 'seldom heard'.*

2. **Design for measurable outcomes**

   What will good look like? What are the health, wellbeing or other measurable outcomes that your work will impact? Your work should improve lives either directly or indirectly, *especially for those who have been historically neglected. Use data to create a granular understanding of what an improved outcome looks like for those with protected characteristics. Capture and use ethnicity data so that it's proportionate for its purpose.*

3. **Be inclusive *and equitable***

   NHS services are for everyone, *but some people require greater investment for equality of outcome. Designing equitable services might mean reaching out more or providing specific services to those who have been historically marginalised.* Make sure people with different physical, mental health, social, cultural, *language* or learning needs can use your design - *even those who don't usually engage with the NHS. Ensure the purpose of any service or app is clearly communicated to the full range of user groups and is based on their needs and behaviours.*

4. **Design for context**

   Don't just design your part of a service. Consider people's entire experience, the infrastructure, *the physical and digital* processes involved. Think about how people begin and end their time with what you are designing. *Ensure you spend time understanding the different social, cultural, historical and political contexts for people from different ethnicities.*

5. ***Start with building* trust**

   People *from different ethnicities and backgrounds trust the NHS differently. Start by first building trust with communities, especially if they are ethnic minority groups. Acknowledge the complex* *history and relationships that people have with the NHS and other public institutions and work to rebuild trust that is broken*. Design things that are reliable and secure. *Set clear expectations around simplified processes.*

6. Test your assumptions

Design for ethnically diverse users from the start to set-up an inclusive approach. Design and test your work with real people. Observe behaviour and gather evidence. Work with subject experts and existing research. Do not rely on hunches.

7. Make, learn, iterate

Work with local, ethnically diverse groups to co-design your solutions. Start small. Experiment with different ways of doing things. Make prototypes to improve your understanding. Test and refine *with diverse people, who have different needs*.

8. Do the hard work to make it simple

Healthcare journeys can be complex. Take the time to understand what you are trying to *solve by working with clinicians and other healthcare staff. Design for people speaking different languages so services are simple to engage with for everyone.* Do not push complexity onto the people using what you are designing. *What feels simple for one user group might not be for others, so ensure you engage with diverse groups of people.*

9. Make things open, it makes them better

Share your learning. Share your work. Be transparent in your design decisions.

Be accountable and have confidence in your solutions. *Work hard to ensure people, from all user groups, understand the purpose of the service or the app as well as how their data is collected and used.*

Appendix 1: Glossary

Accessibility

Accessibility means making a service or app usable by as many people as possible. Generally, this is about people with physical or mental health disabilities. Accessible practices benefit other groups such as those with poor internet mobile connections or low levels of English, to name a few. The accessibility regulations came into force for public sector bodies on 23 September 2018. They say you must make your website or mobile app more accessible by making it ‘perceivable, operable, understandable and robust’.[118]

Agile

A method of project management, used especially for software development, that is characterised by the division of tasks into short phases of work and frequent reassessment and adaptation of plans. Agile teams move at pace by breaking down tasks into sprints, which is why it can be difficult for them to focus on slower, more complicated issues like addressing systemic racism.

Co-design

Co-design is about designing with, not for. It is a design-led approach that actively involves users and stakeholders from the beginning of a project, right through to roll out. This means collaborating with everyone upfront who might be impacted by the solutions. Here, teams actively seek input and feedback, based on the lived experiences of people to iterate their work. Co-design begins with building conditions for genuine, safe and enough involvement of people with diverse backgrounds and lived/living experience.[119]

Data

The facts and statistics collected together for reference or analysis. In this report, we are mainly referring to quantitative data on demographics, clinical outcomes, and digital behaviours of NHS service users (or potential users) and usage of the apps.

Design

Design is how we can make better change happen. It’s a structured approach and mindset of making intentional strategic and operational decisions, based on an understanding of users and their contexts. It helps create a shared understanding, while helping teams tackle problems in creative ways. Design is driven and refined by user research and co-design. It is often an iterative process that addresses the whole user experience and outcomes. Design is key to the development of digital products like apps or wider services.

[118] Gov.uk. “Understanding accessibility requirements for public sector bodies.” GOV.UK, 9 May 2018, https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps. Accessed 1 July 2022.

[119] McKercher, KA “What is co-design? — Beyond Sticky Notes.” Beyond Sticky Notes, https://www.beyondstickynotes.com/what-is-codesign. Accessed 1 July 2022.

Digital

The NHS has a range of digital clinical systems such as electronic patient records and online consultation tools and even wearables as part of telehealth. Digital also includes social media and mobile applications. In this report, we refer to healthcare services that are delivered through online and mobile channels when we talk about 'Digital'. Yet, digital is also a mindset that both enables and is evolved through organising for how digital services are delivered. We agree with Tom Loosemore's definition here which defines digital as 'Applying the culture, processes, business models and technologies of the internet era to respond to people's raised expectations.'[120]

Digital transformation

This is how organisations organise and structure themselves and their teams so that they can design and deliver seamless services digitally. This also includes working in a more agile way, across disciplines and functions to truly maximise the advantages of digital. Digital transformation is not just about transforming technology but is also about working with people to transform culture and ways of working.

Digitalisation

Here the focus is on transforming business activities and services with technology. This is the opportunity to rethink how operations and capabilities can be completely reinvented, offering new possibilities and ways for organisations to create value.[121]

Ethnic health inequalities

Ethnic inequality refers to differences in opportunities for different ethnic groups in a population. Health inequalities are differences in health status that are driven by inequalities in society. Health is shaped by many different factors or wider determinants, such as housing conditions, deprivation, education, employment, material wealth, psycho-social stress, discrimination as well as local health services. Health inequalities represent the cumulative effect of these factors over the life-course; they can be passed on from one generation to the next through maternal influences on baby and child development. In health, Black and minority ethnic groups generally have worse health than the overall population, although the patterns of ethnic health inequalities are very diverse.

Equity

Equality means each individual or group is given equal resources or opportunities. Equity recognises that each person or group has different circumstances and allocates the exact resources and opportunities needed to achieve an equal outcome for everyone. While both promote fairness, equality treats everyone the same regardless of need, equity treats everyone differently depending on their individual need. Equity is necessary to reach equality.[122]

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[120] Loosemore, Tom. "Definition of Digital: Applying the culture, processes, business models and technologies of the internet era to respond to people's raised expectations. — Public Digital." Public Digital, 28 June 2017, https://public.digital/definition-of-digital. Accessed 1 July 2022.

[121] Holliday, Ben. Multiplied: How Digital Transformation Can Deliver More Impact for the Public Sector. TPXimpact Holdings plc, 2022.

[122] "Equity vs. Equality: What's the Difference? | Online Public Health." George Washington University, 5 November 2020, https://onlinepublichealth.gwu.edu/resources/equity-vs-equality/. Accessed 1 July 2022.

Health outcomes

Health outcomes measure a change in the health status of an individual or a group which can be attributed to intervention. Utilising health outcomes will determine the impact of the process of care or intervention on lives by using specific measures before and after treatment. Measures must be chosen carefully to ensure the test, scale, or questionnaire records what it aims to record (whether it is valid and responsive) and is sufficiently well described to ensure that everyone who uses it does so in the same way, so that it is reliable.

Inequalities

Inequality refers to the phenomenon of unequal and/or unjust distribution of resources and opportunities among members of a given society. In this report, we are primarily referring to race inequalities, although gender, sexuality, poverty, age, disability are also important considerations in healthcare and equality. These inequalities also often intersect, with people facing multiple types of inequalities at the same time, creating a greater need for more wraparound support.

Racism

Racism can be structural, systemic or interpersonal in nature: structural racism refers to the processes that lead to disadvantage in accessing economic, physical and social resources; systemic racism is legitimated by discriminatory policies and norms embedded in large institutions (such as the NHS), and captures a broad range of practices that perpetuate differential access to services, and opportunities within institutions and the wider system; interpersonal racism refers to discriminatory treatment during personal interactions, such as verbal or physical abuse but also refers to acts of ignoring or avoiding people due their ethnic background.[123]

Systemic racism

Systemic or institutional racism refers to practices or attitudes that limit an individual's or a group's right to the opportunities generally available because of ethnicity. This is deeply ingrained in societal structures and difficult to solve. It results in ethnic inequality (see above)

Inclusive design

The British Standards Institute (2005) defines inclusive design as: 'The design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible ... without the need for special adaptation or specialised design.'

User- centred design

User-centred design process (UCD) is also called human-centred design process. Human centred design processes for interactive systems, ISO 13407 (1999), states: 'Human-centred design is an approach to interactive system development that focuses specifically on making systems usable. It is a multi-disciplinary activity.'[124]

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[123] Kapadia, Dharmi, et al. "Ethnic Inequalities in Healthcare: A Rapid Evidence Review." NHS Race and Health Observatory, February 2022, https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf. Accessed 6 May 2022.

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Appendix 2: Requests for research sent to NHSBT and NHS Digital

Project documents shared with the NHSBT and NHS Digital teams

A. Project overview: Review of NHS managed national patient and public mobile applications (apps) Proposed Research Approach - 8 Feb 2022

Who we are

Our team works for TPXimpact (formerly known as FutureGov) and we have been commissioned by the NHS Race & Health Observatory to conduct research on how ethnic inequality can be reduced through NHS apps.

Project Goals

The goal of the project is to conduct actionable research that can shape future guidelines to reduce ethnic inequality in the usage of NHS apps and digital services.

The project will review the usage of three apps: NHS BT's Give Blood app, the core NHS app and the NHS COVID-19 app.

Research questions

We want to focus on the role digital and apps are playing in addressing 2 evidenced challenges we know NHSBT and NHS are respectively experiencing:

- The fact that less than 5% blood donors are from BAME backgrounds, and that there is a shortage of donors of RO bloodtype. Source
- The fact that the ethnic groups with the lowest proportion of people who had received three vaccinations were Black Caribbean (33.9%), Pakistani (37.8%) and Black African (37.9%). Source

We want to explore how the two organisations are using digital and data to understand or address these challenges, and what are the unrealised opportunities to do so.

- How is digital seen as part of the solution or the problem?
- What aspect of the digital service of apps today is addressing this problem?
- How evidence or data are the organisations using to make informed decisions?

- Would more data be helpful - what kind of data?

- What kind of guidelines would be helpful to help address these challenges?

We also want to explore these issues from the community's perspective, by speaking to those from BAME communities with low rates of blood donation/ covid vaccination.

Research Methods

In order to answer these questions, we are proposing to use the following qualitative and quantitative research methods:

1. **Quantitative data from NHS apps (where available):**

   We'll analyse available analytics data from the 3 NHS apps in order to look at the variation between different ethnic groups, based on the most granular level of demographic data available. To understand how people discover and use the apps, we will focus on the following analytics (subject to availability):

   - Download rates

   - Percentage of repeat users

   - Average number of visits

   - Rate of completion for different tasks (for instance, registering to donate blood, registering to get vaccinated, registering to see GP)

2. **Stakeholder interviews of NHS product owners**

   We will interview the service owners and/or design leads behind the three apps to understand current considerations and assessments made around ethnicity and equality during the design process, as well as what best practises are being followed in terms of equalities assessments.

3. **Digital survey**

   We will design a short survey (requiring no more than five minutes of participant time to complete) to reach a broader audience of Black and minority ethnic groups, focusing on the contributing factors identified in the focus groups. We will launch the survey through channels available to the NHS apps and NHS RHO - for example, social media and in-app communication.

4. **Two focus groups**

   We'll propose two focus groups with members of ethnic communities in locations across the UK. We will recruit respondents for these groups by contacting local ethnicity-based community groups (for instance, the Manchester Chinese Centre, Brixton Splash, Bradford Pakistani Women's Club) and through advertising in channels available to the NHS and NHS RHO (for example, advertising through social media, through local NHS trusts, through in-app pop-up notifications). We will design these focus groups to uncover individual participants' experience with the apps.

Project Outcomes

The project will result in a published report which includes insights and recommendations (short and long-term) by end of May 2022.

Data Handling

TPXimpact have signed a Data Protection Impact Assessment with the NHS RHO aligned with requirements by NHS Confederation.

B. Request email sent by TPXimpact to NHS Digital

Date sent: 8 Feb 2022

Hi [Name Redacted],

Thank you for your time last week. As promised, we've attached the background to this work as well as our detailed proposal. And ofcourse, please feel free to ask any questions. We're also happy to have a planning call incase that's easier.

Our last conversation was super helpful in helping refine our focus for our research. Instead of understanding disparity widely, we want to understand it through the lens of a current challenge. For NHS Digital, we are particularly interested in understanding more about how Black Caribbean (33.9%), Pakistani (37.8%) and Black African (37.9%) are the ethnic groups with the lowest proportion of people who had received three vaccinations.

This includes understanding:

- How is digital seen as part of the solution or the problem?
- What aspect of the digital service of apps today is addressing this problem?
- How evidence or data are the organisations using to make informed decisions?
- Would more data be helpful - what kind of data?
- What kind of guidelines would be helpful to help address these challenges?

We have 2 asks around this: Qualitative & Quantitative

Many thanks,

Megha

A. Qualitative

It would be great to speak to people in the app teams to get a qualitative understanding of considerations, gaps and opportunities around access and usage of apps and digital services to understand or address this challenge.

Could you recommend 2-3 people we could speak to about:

1. Considerations around digital exclusion and health outcomes. Any interventions that have been tried or data used, particularly for reaching out to people of these three ethnicities

2. Making apps usable to a wide range of users i.e. addressing language barriers, digital literacy, working with communities on the ground etc.

3. Awareness of apps i.e. marketing, re-directing people to apps within the user service journey etc. and differences in approaches for reaching out to different audiences

These could be people from the product teams - product/service owners, research or design leads as well as people working in marketing. These conversations would be an hour long.

B. Quantitative

We are looking for some Quantitative Data as part of our discovery approach.
This could be:

1. The first thing we want to establish is the relationship between digital usage (and specifically app usage) and behaviour of our population. In short, does using the app drive vaccinations?

Data request:

- What percentage of people who got (1/2/3) vaccination(s) use the app. If this can be cross referenced by ethnicity and socioeconomic background, great. We are looking to see if downloading the app after the first vaccination increased likelihood of getting the second, and after the second, the third. If we can see x% of people with only one vaccination have the app, but x+10% of people with two vaccinations have the app, we can at least prove correlation.

2. Where there is ethnic disparity, what is driving the disparity? In short, once controlled, is the fundamental variable ethnicity (or closely related variables such as language or religion), or is it broader such as disproportionate levels of some socio economic groups or locations.

Data request:

- Breakdown of app and website users by ethnicity, age, language, religion, location, socio economic background, operating system/phone type (and anything else you capture!)

3. Is it economical to evolve the app design and marketing, or would other behaviour changing activity be more effective in closing the vaccination gap between different ethnicities?

Data request:

- Media plan of the previous year, with breakdown on targeting by ethnicity if possible for digital marketing activity. (Looking for any disparity in the CPA between any ethnicity groups, to test whether it is harder to convert to app, or have marketing activity been more skewed towards other behaviour changing activity such as outreach or website promotion for certain groups.)

I also wanted to note that TPXimpact have signed a Data Protection Impact Assessment with the NHS RHO aligned with requirements by NHS Confederation.

Please let us know if you need any further information,

Looking forward to hearing from you,
Megha

C. Follow up email sent to NHS Digital after initial conversation
Date: 28 Feb 2022

Hi [Name Redacted],

Hope you had a good weekend and thanks for asking. We had a very rich conversation with the team, which has been super helpful in shaping the work. Thank you so much for helping make the call happen.

In terms of next steps, we are now about to start recruiting for focus groups. Off the back of this, we are planning to run co-design sessions to shape actionable guidelines and recommendations. We would love to have the nhs digital app team (along the COVID-19 and nhsbt app teams) be part of co-designing these - these should be taking place ideally early April. We'll be sending invites for these in the next few weeks.

In the meantime, the team have spent the last week consolidating and synthesising literature and interviews. We had a couple of follow-up asks and questions - some of which we referenced in the call as well. These are:

Asks

1. Could we access any relevant panel research that speaks to any decisions made around access or accessibility ethnicity perspective, especially from a Black Caribbean/African or South Asian perspective

2. Could we access the regional level data, the team mentioned on the call - is this the same as the data on the NHS dashboard?

Questions

1. We are keen to understand more about working with communities on the ground and researching with panels - what are some limitations, advantages, good practice etc. around this approach.

2. We are also interested in unpacking appetite/ need for different types of data, what data could be ideal, data limitations and why they exist.

Please advise on how we can access some of the existing research and/or have a follow-up conversation with relevant people. The call attendees were happy to be contacted again - am happy to follow up with the group as well.

Many thanks,

Megha

Request email sent to NHSBT
Date: 11 Jan 2022

Hi [Name redacted],

How are you? To introduce myself, I am a Principal Consultant at TPXimpact (previously Futuregov). Our team are supporting Owen at the NHS RHO on a project to understand how digital experiences of NHS apps can be improved for people of diverse ethnic backgrounds, improving health outcomes.

We are keen that the project aligns with the existing goals and initiatives to broaden outcomes and access within NHS BT.

Our project includes qualitative and quantitative research components, but we also want to include the relevant stakeholders within NHS BT in co-design sessions to ensure that our research questions and final design recommendations are useful to your existing and future digital design processes.

We would appreciate an introductory meeting with you to overview the project goals and discuss:

- Understand what data is available and accessible that can help us understand how people of different ethnic backgrounds access and use the apps today:
- Demographic information: User population breakdown by ethnicity, age, disability, socioeconomic background, region, operating system, brand of phone - is this possible?
- Analytics on usage: app download rates, number of sessions / length of sessions, rates of registering to donate, etc.
- Discussion on how best to share data and ensure privacy/compliance
- Identify the most appropriate internal design stakeholders/ service owners for NHS App and NHS COVID app to talk to and engage throughout the project to understand your priorities and design processes in this area

Let me know how that sounds and what your availability is for an intro chat this/next week?

Feel free to introduce us onwards to anyone else who might also be relevant to speak to at this point as well.

E. Follow up from call with NHSBT on data

Date: 2 Feb 2022

Hi [Name redacted],

Huge thank you for taking the call yesterday and being so helpful on the project.

I have CC'd zung and megha, who are also working on the project. I just wanted to follow up on the next steps, and see if we can help in any way. Zung is currently filling in the Data protection impact assessment (as seen below).

So in terms of asks from us, the following would be very exciting:

- sending two econometric studies on ethnicity (independant and kantar)
- contacts for media planning and impact (are you happy to introduce us to Tom?)
- contacts at donor centers administration staff
- an update as to how we can help with the data board approval

after the data access is agreed, the next steps are

- accessing a cut or summary of the pulse data that would allow us to look at donations and ethnicities
- doing the longitudinal study on people from 1995 - 2020, comparing individual donor downloaded the app vs never downloading the app, in terms of blood donation frequency

- it may be for after the conversation with data board team, but it would be great to understand what our role in creating these would be. Very happy to take your lead on this, but also aware it may sink into your time.

All the best,

Conor

F. Follow up from call with NHSBT on user interviews

Date: 4 Feb 2022

Hi [Name redacted],,

Thank you for your support in helping us gather relevant data. Conor has been raving about his chat with [Name redacted]..

Now that we have a better sense of data, it would be great to speak to people in the app and marketing teams to get a qualitative understanding of considerations, gaps and opportunities around access and usage of apps and digital services.

Based on our call, we think [name redacted] would be great to speak to. Please let us know if we can reach out to her directly or if you could help get in touch.

Also, could you recommend people we could speak to about:

- Considerations around digital exclusion and health outcomes and any interventions that have been tried in this area
- Awareness of apps i.e. marketing, re-directing people to apps etc.
- Making apps usable to a wide range of users i.e. addressing language barriers, digital literacy, working with communities etc.

These could be people from the product teams - product/service owners, research or design leads as well as people working in marketing.

Looking forward to speaking with you,

Many thanks,

Megha

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