



**Uniting ‘Bottom Up’ and ‘Top Down’
perspectives to transform digital health
experiences.**



Condensed report

March 2021

Executive summary

The Equalities, Health Inequalities and Digital Inclusion (EHIDI) programme was stood up within NHSX in response to the prevailing health inequalities surfaced during the first wave of the pandemic. The aim of the programme was to embed equity and inclusion considerations across the organisation by equipping teams with the confidence and know-how to address digital health inequalities in their areas of work.

For a universal public service like healthcare, its vital service providers understand the lives, needs and preferences of a very diverse range of people and communities. Service providers, designers, commissioners and leaders need to be able to ask lots of questions, explore and test different ideas and explore the inevitable practical trade-offs against time, money available and competing priorities to get to a well-considered policy, strategy, experience or digital product. All of these activities are best done in a continuous conversation (of equals) between people using services and those delivering services. Our model enabled that to happen.

We combined an 'inside, looking out' view taken by people inside the organisation, uniting it with a 'outside, looking in' view of the wider community of people using services. Or a 'bottom-up' meets 'top-down' if you prefer.

It is a more inclusive and diverse approach, which delivers richer understanding, provides stronger foundations for policy, service and product development, lessens the risk of failure and increases the chance of successful delivery. Four main recommendations have emerged from our time at NHSX and can be found on page 19.

1. Value pragmatism
2. Listen & act
3. Race is a bad proxy
4. Inclusion as a behaviour

The team were brought into NHSX to act as advisors and collaborators, positively disrupting the landscape that would propagate best practice. We have valued this experience of piloting such an innovative and collaborative programme. We hope you can build on our practice in order that your teams produce **great tech** that is inclusive by design from the start and you reach **all** the communities the NHS serves.

This report has been designed to share our methodology so that the investment in the pilot results in ongoing learning and knowledge sharing across the organisation. Also available are project reports with detailed insight from each research challenge.

Introduction

Our Head of Programme, Shabira Papain, spent May-September 2020 listening to the needs of various teams across NHSX, NHSD and NHSE/I; sharing good practice and offering insight with a view to design a programme that would address digital inequalities whilst meeting the needs of teams amid the rapid channel shift induced by the pandemic.

Using the data from the PHE¹ June 2020 report, the programme focused on West Birmingham and East London as well as communities who experience racism², with an appreciation of intersectionality and protected characteristics. We were to pilot a 6-month programme which would bring a digital health inequalities lens to digital transformation.

Building on the insights from the PHE paper, the NHSD³ report and the collaborative report published by Healthwatch England *The doctor will zoom you now*⁴, we co-designed the programme focused on surfacing the experiences of underrepresented communities to support informed decision making.

In our team we have Subject Matter Experts from Community Development, User Centred Researchers/Designers and Equity Diversity Inclusion (EDI) Content Producers/Designers. This unique mix of skills enabled us to create capacity whilst embedding capability. In this report, we will share the breadth of work undertaken by the EHIDI team in collaboration with the many teams we supported during the pilot.

Before we dive in...

There are a couple things that you need to be aware of before we get stuck into the detail.

Firstly, our approach is grounded in the belief that tackling digital health inequalities requires a multi-level, multi-disciplinary and multi-sector response as bringing multiple perspectives increases the opportunity to reveal and tackle the barriers to exclusion.

Our team offered two strands of expertise: Person Centred Research/Design and Inclusive Content Production/Design. The glue between these two offers was our Community Outreach team which brought community development expertise into the folds of the NHS. We maximised the strengths of each team member, collaborating across our disciplines to learn from and with each other and the teams we supported.

Secondly, we were united by the following principles which underpinned our approach:

1. Actively seek and listen to voices that are underrepresented.
2. Engage with people at a local level and where possible bring local knowledge to regional and national level.
3. Piggy-back on good work that is already established.

¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

² <https://incarts.uk/%23bameover-the-statement>

³ https://vanderschaar-lab.com/papers/Ethnicity_COVID19_Cambridge_NHS.pdf

⁴ <https://www.healthwatch.co.uk/blog/2020-07-27/doctor-will-zoom-you-now>

4. Share good practice with other teams, localities, regions, sectors.
5. Strive for services and products grown together with the communities you serve.
6. Aim to create agency rather than passively bestowing products upon communities

Lastly, the team is made of predominantly people whom public services and research bodies may describe as BME or BAME. These acronyms are not how we describe ourselves. Though we understand the positive intentions behind these terms, we will instead name what we mean by using the phrase *people who experience racism*⁵ as well as acknowledging intersectionality and the importance of protected characteristics.

Let's get started...

PART 1. Community Research

An innovative part of the approach to understanding health inequalities and digital exclusion was to stand up a team of community researchers, each living and working in different communities. Some came with considerable experience of community health research and others were new to formal research methodologies. All were community leaders with a background in community development. An often-unacknowledged part of tackling health inequalities is creating meaningful and well-paid employment that benefits individuals and families as well as providing social impact that has the potential to take whole communities out of poverty. When Nye Bevan dreamt of the NHS in 1948, he was dreaming of a system which tackled inequality. As one of the largest employers in world, the NHS has its foundations on this premise. Our model has its foundations in Bevan's vision, and we benefitted from this approach.

1.1 Research strands

During the pilot, the team undertook a research programme with three work strands:

1. Lived experience community research with underrepresented communities
2. Research collaborations with NHS teams
3. EHIDI recruitment for NHS teams

The **first** series of 'lived experience' research projects aimed to capture and understand the living experience of underrepresented communities during Covid and their experience of three key services: GP Booking and Consultation, 111 and Urgent Care and Maternity Services.

The **second** strand of work was a series of collaborations with other NHS teams to help support more inclusive and diverse research and insights across a wide range of programmes. This strand was focused on offering person centred research expertise with an EHIDI lens. We

⁵ This term provides acknowledgement of the harm caused, and gives context in many instances where a collective term is sought. It will also require you to then articulate who you are referring to, and may, depending on context, refer to Western Asian people, Irish people, Jewish people and others whose oppression is not captured by current terminology. Please use with awareness the phrase 'people who experience racism', and don't make it an acronym ever. <https://incarts.uk/%23bameover-the-statement>

collaborated closely with NHS teams to deliver a professional review of 13 Total Triage tools as well as redesign the contact preferences survey.

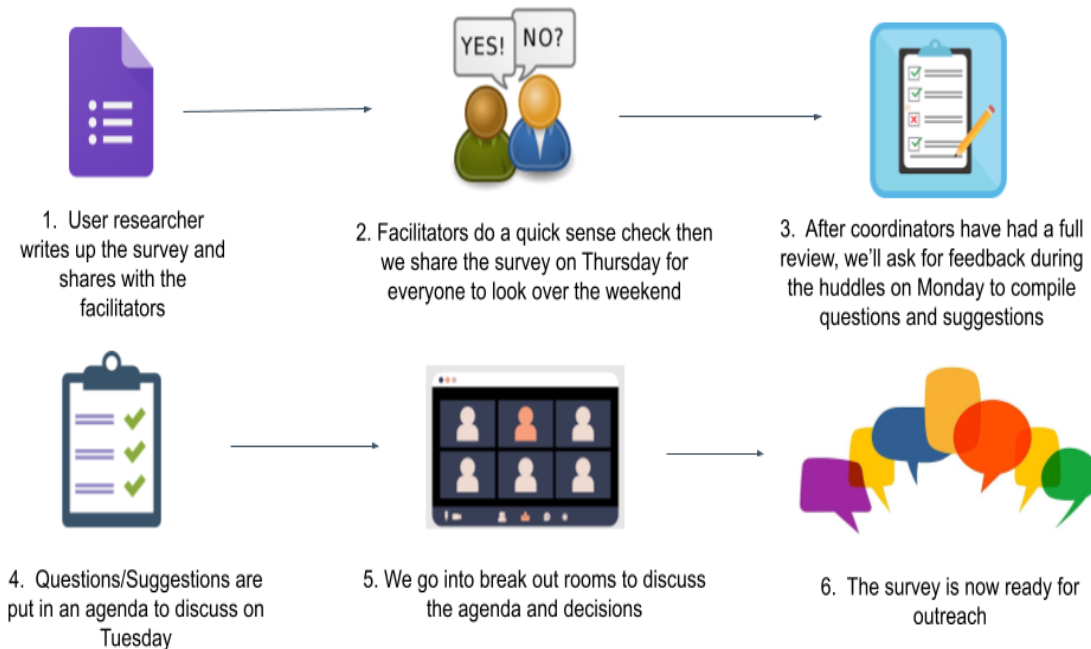
- **Digital First Primary Care** on the national programme developing the usability and integration of GP booking and consultation systems.
- **Digital First Primary Care** on developing and testing the 'triage to community pharmacy' new service.
- **Login and Identity team** to help create a more diverse and inclusive piece of research around peoples contact preferences.

The **third** strand focused on recruiting underrepresented communities to take part in research ensuring the voices of people who experience racism were heard. We supported NHS teams to prepare detailed briefs to ensure the *right* kind of diversity was achieved. For example, focused on communities who experience racism as well as an intersectionality approach to create profiles so as not to use ethnicity as a proxy on its own and worked across protected characteristics. We used a matrix to focus on communities most at risk of poor outcomes and therefore focused on ethnicity alongside socio-economic status, education, postcode, language, digital skills, age, gender and disability.

The community researchers were briefed on the profile and given interview slots and a research overview. They used this to reach out into their community networks to invite people to take part in the research. We were able to support digitally excluded participants as well as participants lacking confidence to speak in English to take part by actively supporting the engagement process. For example, acting as interpreters, arranging telephone calls or taking participants through the video call process.

- **Medical Devices Team** - exploring patient / consultant decision making tools in relation to heart related medical devices.
- **Innovation Lab**: Admit Me- research to see how we can improve patient experiences when arriving at a hospital.
- **Innovation Lab**: Parents who are managing the treatment of children with chronic illnesses and who are taking medications
- **Wellness Hub Discovery**: how future digital services might support the wellbeing and prevention agendas and the impact it would have on health inequalities
- **NHSD Antigen testing**- research focused on people with protected characteristics
- **NHSD Test & Trace**- research with people who experience racism on attitude towards T&T.

3.3 Our research cycle



Feedback:

To outreach workers: findings are shared with coordinators in regular Tuesday sessions or monthly practice development meetings. Towards the end of the pilot, we were also able to update the team with news about who the findings had been shared with across the NHS and the impact this was having on thinking.

To participants: at the start of the programme, we made the commitment to share the impact of our approach with local communities. This is an integral part of the approach which offers an opportunity to demystify user research, respects the involvement of communities and works towards building trust through openness. We have designed and developed an animation which simplifies our approach and shares some of what we learned during the pilot.

PART 2: Piloting our model

2.1 There are five key aspects to the model we have been piloting

Community Outreach Coordinators

At the heart of our work are a team of community outreach workers, people living in communities seldom heard by the NHS. They provide deep understanding and a trusted connection to seldom heard communities. They also provide practical support to take part and aid inclusion of a more diverse range of people to participate; helping with writing, translating materials, providing digital access.

Co-Design at Every Stage

From our initial thinking, to the development of research approaches and materials, each stage is co-designed in our weekly meetings with the project team (which includes all community outreach workers).

This co-design approach brings considerable community knowledge and diversity of thinking into the early stages of each research project and allows us to explore what areas or questions should be covered, to highlight any sensitivities we should be mindful of and to explore different ways we might explore potentially sensitive but important research subjects, for example personal healthcare experiences, household incomes and finances, identity, education and knowledge finding.

Our team also 'road tested' questionnaires, surveys and research tools ahead of fieldwork.

Creating Continuous Conversation

We aim to create a conversation between communities and the NHS staff designing and delivering services. Creating a continuous conversation means we can keep noodling away at the most complicated issues to find a solution that works well for as many people as possible.

Part of having a good conversation is about closing the loop. It's important to provide feedback to participants about what happened as a result of the research they contributed to.

It's inclusive

Ensuring that all members of the community can participate by:

- Working with outreach coordinators who can interview and translate to languages used in the community
- Providing different options for completing research (self-completion or assisted)

It's based on reciprocity

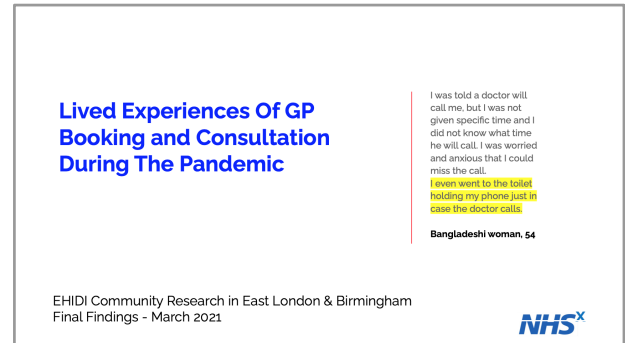
Our approach is driven by reciprocity, exchanging value not 'extracting information'. This key community development principle is considered and actioned at every level:

- Between NHSx and Community Outreach Workers & Facilitators
 - Mentoring and coaching
 - Developing skills and experience in synthesizing qualitative and quantitative data, research design, and report writing
- Between Outreach workers and participants
 - Providing signposting to relevant NHS services
 - Listening to people without judgement and offering an empathetic ear

PART 3: Research Delivered

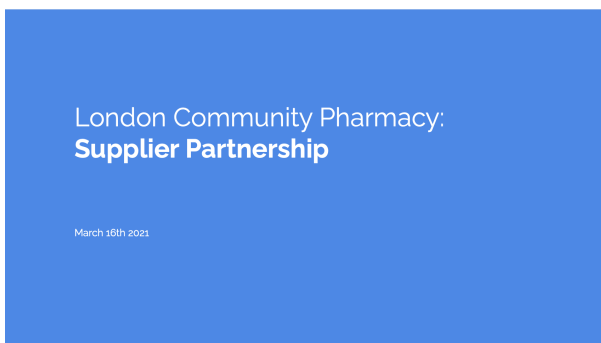
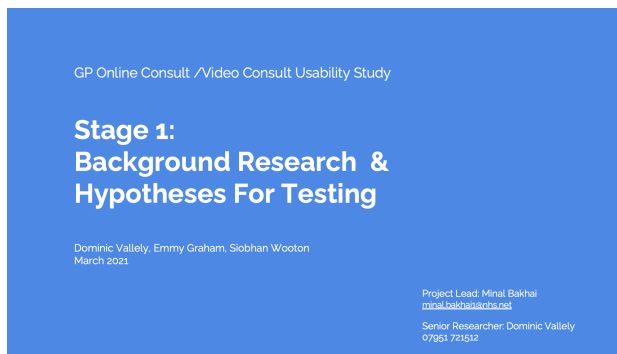
3.1 Lived Experience of Access to Primary Care during Covid

- Over **250** hours of conversation in **225** sessions with people who experience racism or have protected characteristics.
- To understand the impact of Covid related changes to accessing your GP.
- To prioritise improvements from a grassroots perspective



3.2 DFPC - Usability Testing of National GP Booking and Consulting Systems

- Professional user experience review of **13 GP booking and consulting platforms** from patient and practice perspective to understand pain points and access barriers, especially for the digitally excluded and other vulnerable groups.
- Development of the next stage of the project; large scale usability testing to support development of 'UX assurance' in GP digital journeys.

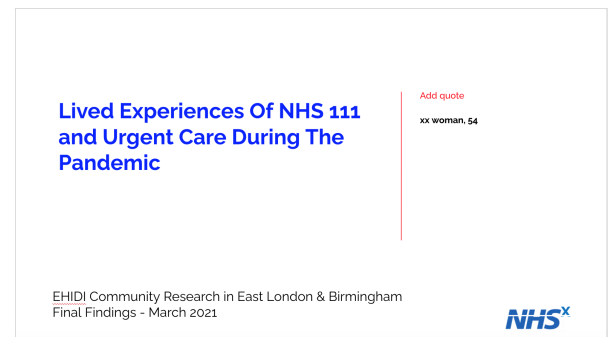


3.3 DFPC - Usability & Concept Testing of Community Pharmacy Referral Pathway

- Initial assessment of proposed user journey and prototype journey
- Helping team develop a scope for prototype testing to support the journey to live pilot
- Meeting with suppliers to discuss, agree, test and iterate approach

3.4 Lived Experience of 111 & Urgent Care

- **325** research conversations with communities with protected characteristics about their experience of 111 and urgent care during Covid.
- Additionally, to explore the reach, understanding and potential outcome of the recently launched 'Call 111 First' campaign.



Access To Primary Care: Perinatal services

Patient Experiences of Perinatal Care During Covid-19 Lockdown

Interim Findings - January 2021
Final report due March 2021

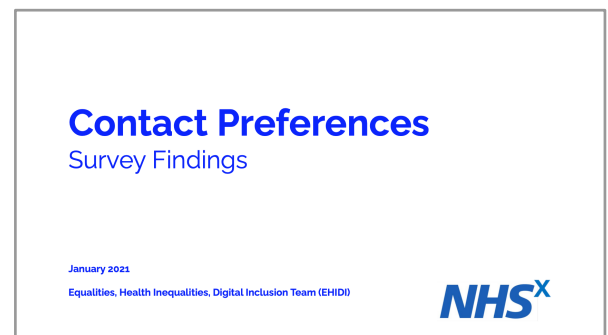


3.5 Patient Experiences of Perinatal Care

- **48** research interviews with Somalian, African, Indian, African/Caribbean and Bangladeshi mothers about their experience of maternity services during Covid.

3.6 Contact Preferences Research

- Working with the Login and Identity team to help devise a more inclusive and diverse approach to research to understand people's contact preferences. We reached **100** people who are underrepresented in research including: self define as digitally excluded, experience racism, NEETs



PART 4: Monitoring & Evaluation

In total, between December 2020-March 2021, we facilitated over **700 conversations** directly with communities traditionally excluded from research totalling over **1050 hours of listening**. On average, we spoke to an additional 8 people for every interview and research conversation. That is a total of **5,600 contacts**.

Whilst community researchers were conducting interviews, they were also providing traditional community outreach support by:

- Listening to the experiences and needs of patients in the community
- Signposting to the right healthcare services in their area

- Providing support and advice - especially relevant during the pandemic when so many in the community felt isolated and alone
- Decoding and translating medical terminology

It is this aspect of the methodology which builds trust from the ground up. We urge you to connect with grassroots organisations who catch the community's national charities and service providers dream of reaching.

Insights

...I am privileged to work with such an amazing team dedicated to bringing about positive change. Work was interesting and it armoured me to help myself by helping others. I would recommend anyone who has a closed opinion to join to see the wider views and impacts of the work we have done. It would help them in the least to change their work ethos positively and help them think about how they affect others around them both privately and professionally. It helps peoples voices to go from 'I didn't know that' to 'why is that?'

...the learning for me was beyond my expectation, I learnt how to present interviews, my writing skills has improved, my confidence has increased and my highlight was presenting to over 100 people from the NHSx.

Learned more then I expected my confidence has gone high I have learned interview skills, I have supported the team and this has able me to work and support others.

I actually learnt more about what the NHS has to offer e.g. NHS 111 service, which I will now be promoting in my personal life, as the information is so useful. I got to hear about agile project management which I will study more once we finish.

4.2 Recommendations

- Value pragmatism:** bring in people into your organisation and teams who have experience of doing the doing. Tackling digital inequalities requires us bringing policy and strategy to life. We need *bridges* in the organisation, people who can do translate good intentions in tangible and pragmatic ways that deliver impact for people on the ground. Add this to JD's to attract diversity into your teams.
- Listen & act:** Don't just invest in listening to underrepresented communities. Act on what is heard. Go back and share the impact of their engagement.
- Race is a bad proxy:** do not use ethnicity as a proxy on its own. Apply intersectional thinking and disaggregate data to avoid seeing communities as homogenous.

- d) **Inclusion is a behaviour:** Inclusion isn't a thing we do. It is a behaviour we demonstrate. There is a gap between what leaders are expressing and how teams, missions and programmes are behaving. This discrepancy will continue to undermine good intentions and needs addressing.

We hope you can build on our practice in order that your teams produce **great tech** that is inclusive by design from the start and you reach **all** the communities the NHS serves.

Contacting Us

We appreciate that there is complexity across the landscape requiring innovative and long-term strategies and we encourage you to reach out if you need additional support to positively disrupt and implement equity, diversity and inclusion strategies in your areas of work.

We are sharing our learning and practice in the interests of the communities we serve. We invite you to build on our methodologies to deepen your own practice and that of your teams.

We could not have succeeded without the support of and expertise of the community researchers who brought rich insight and wisdom to the process. Shabira Papain will continue to work with this team as part of People Street. Do get in touch if you want to collaborate.

Shabira Papain

shabira@peoplestreet.uk

07715905585



As Sir Michael Marmot notes

'...if health has stopped improving it is a sign that society has stopped improving'.