



Digital

# Test and Trace- researching with community groups

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# What did we do?



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# What did we do?

- We conducted user research with 12 participants, recruited for us by community groups based in different locations
- During the research we explored people's attitudes, beliefs and experiences around coronavirus testing, the pandemic as a whole and how this affected day to day living
- We also explored the concept of taking part in regular coronavirus testing, even without having symptoms and the barriers that people face when trying to access these services
- We also looked at the NHS website and some new content about testing, to see how easy or difficult this information was to digest and understand



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**Who did we speak  
to?**



# 12 participants

## Age

18 – 29 years x 6  
30 – 59 years x 3  
60+ years x 3

## Location

London x 3  
Central/ North East x 3  
West Midlands x 6

## Ethnicity

Black African & Black Caribbean x 4  
Pakistani x 2  
Bangladeshi x 2  
Indian x 2  
Mixed or multiple x 1  
White x 1

## Gender

Male x 6  
Any other gender identity x 6

## Income

Less than £30k p/a x 9  
More than £30k p/a x 3

## Other demographics

English not first language x6  
Asylum seeker x3  
English not only language x11



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# Why inclusive research



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# Why inclusive research?

- Current User Research in NHS Digital lacks diversity of voices, because we rely on agencies to reach participants and these agencies are not rooted in local communities
- Failure to capture these voices can lead to NHS products and services being designed in a way where they have the potential to exclude people who are less engaged digitally and emotionally
- The importance of inclusive research has been highlighted during the pandemic as the government, NHS and other organisations need to ensure everyone has access to the information and resources they need to manage their own health and the health of others (although we recognise it is by no means a new problem)

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# The community networks





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# The community networks

## Three networks chosen by location

- Smartlyte - West Midlands
- IFB Gaming – London & South East
- Learn for Life - Sheffield

**How did we  
approach this  
research  
differently?**



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# How we approached this research differently

- We reached out to partners in community networks to recruit people we would not normally be able to talk to using our existing recruitment methods
- We didn't allow any other observers in the research sessions, just the researchers
- Conversation often moved into different topics from our discussion guide and it was more participant-led
- Learned (gradually) to bring ourselves into the sessions rather than try to be neutral to build trust and not portray ourselves as being authoritative



# What we heard



# Impact of the pandemic



# Bringing people closer together

**People told us that the pandemic has brought families and communities closer together**

*“ we knew each other's strengths and weaknesses”*

*“ people are now appreciating what they had”*

*“ in a way it was positive to bond with each other during the first lockdown”*

**People also told us they have been involved in organizing community activities and volunteering for the NHS**

**Making sure others have access to information in their own language has also been something keeping communities together**

# Fear for own health and the health of others

**People told us that they were worried about their health and the health of loved ones**

*“ if something happened to us what would happen to the kids, it was a scary moment”*

*“we were so scared”*

*“ there will be too many people there, so I'll go when it is quiet, want to find out when it is safer for me to go”*

**People also hear stories from others about people they know and their behaviour, making them more fearful about going out**

# Knowledge of coronavirus





# Knowledge of coronavirus was very mixed

Levels of knowledge of coronavirus varied from person to person, ranging from different symptoms to theories behind the pandemic

*“Yes, I know the symptoms... constant headache, sore throat at times, sneezing”*

*“People saying that's it's a planned epidemic by the government to put chips in people's bodies.. crazy things like that- it did seem like that as first”*

## Obtaining information on coronavirus has been a combination of news sites, videos and social media

- People also hear information from friends, family, WhatsApp groups, and other parents, not all of which are believed by people when the information becomes more extreme
- Some people don't have access to online information or information in the language they speak at all

**All this knowledge came from a variety of different sources**

# Knowledge of coronavirus testing



**People didn't  
know about the  
different  
coronavirus  
tests they could  
take**

**Some people thought that there was only 1 test and were unaware of any other method of getting tested for coronavirus**

*“ I thought it was just one test”*

**When approaching the terminology PCR and LTR, most people didn't know the difference**

*“I don't know what PCR stands for.. I think it's a kind of test centre”*

**Those who did know the difference tended to have children at school**

# Understanding the concept of regular/ lateral flow testing had mixed responses

**Some people didn't think these tests applied to them**

*"My son is at school. But I'm an adult, I wouldn't expect myself to be tested twice a week... I'm not a key worker"*

*"Unless I'm in a high- risk group, I don't see why I would"*

**Some people also thought they might be a waste of NHS money and resources**

*"Why would we waste NHS money doing that?"*

*"I think it's a brilliant idea, but it would put strain on resources"*

**Most people  
didn't know you  
could have and  
transmit the  
virus without  
having  
symptoms**

**When talking about why people would get tested regularly, it was perceived that you would only get tested if you had symptoms**

*" I wouldn't get a test if I knew that no one in my house had the virus or symptoms"*

*" I didn't actually know that"*

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# Getting involved in regular testing



# There is concern about the accuracy of the rapid flow tests

When exploring with people about taking part in regular rapid flow testing, there was some speculation about the accuracy of the tests

*“It’s good to get a quick result, but there is that doubt about if it’s right, so I’d still feel scared for my family’s safety”*

*“If it was negative this week, the following week positive even though I haven't been anywhere, then week after negative again - it would put me off, it's not a guarantee ”*



# How to access the tests was important

**How people got access to the tests played a part in deciding to take part in regular testing**

*"I'm lucky to have the testing centre not far from my house, but if it was far from my house, it would be problem if I need to catch a bus... If I don't have enough money"*

*"Not sure if I misread it but I couldn't see anything about kits being sent home"*

# Testing the website



[Home](#) > [Health A to Z](#) > [Coronavirus \(COVID-19\)](#)

# Testing for coronavirus

Get a test to check if you have coronavirus, find out what testing involves and understand your test result.

## [Check if you can get a test](#)

Find out if you can get a coronavirus test if you're not sure what test you need or how to get tested.

## [Getting tested if you have symptoms](#)

Get a free PCR test to check if you have coronavirus.

## [Getting regular tests if you do not have symptoms](#)

Find out if you can get regular rapid lateral flow tests if you do not have symptoms and why regular testing is important.

## [How to do a test at home or at a test site](#)

Find out how to do a test on yourself or someone else, and understand what happens at a test site.

## [Test results](#)

Find out how you get your coronavirus test result, what it means and what you need to do.

## [Antibody testing to check if you've had coronavirus](#)

Find out what a coronavirus (COVID-19) antibody test can tell you and who can get a free test.

# Some of the labels caused problems

Some of the labelling caused confusion, particularly when people thought there was only 1 test

This gave people too many options to choose from, resulting in almost everyone just clicking to get a test regardless of what type we asked people to look for

## Check if you can get a test

Find out if you can get a coronavirus test if you're not sure what test you need or how to get tested.

## Getting tested if you have symptoms

Get a free PCR test to check if you have coronavirus.

## Getting regular tests if you do not have symptoms

Find out if you can get regular rapid lateral flow tests if you do not have symptoms and why regular testing is important.

# Videos helped to explain things

People expressed to us that in general they watch videos, and they help explain complicated things to them

The videos were not found organically on the website pages but once prompted to watch them, understanding of what regular rapid flow testing was and why it would be a good idea increased

People noted that the video didn't explain who was eligible for regular rapid testing, which is one of the key pieces of information they need in order to take part

*“I'd probably go straight to the video, the writing was just too much, so I'd just watch this”*

# What are the barriers for inclusion?



# Barriers people face when accessing important health information and services



Not having access to a digital device or the internet



The information is not in a language they understand



Fears over the safety of themselves and people they care about



Trying to navigate complicated websites and terminology

**Experiencing 1 or a combination of all these barriers can occur at any point and can prevent someone making sure they are up to date with all the information and making the right decisions for their own health, and the health of others**

# How this research has impacted NHS.UK





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# How has this impacted research at NHS Digital

- We are changing the methods we use to reach people to take part in research for nhs.uk and NHS digital services
- We are making our research more inclusive and our services more accessible
- We are sharing our learning across our research community and within service teams
- We are continuing to strengthen our community networks and relationships
- We will continue to conduct research with diverse participants and see how our services and information can best suit their needs

# How this research has impacted the participants



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# How has this research affected the participants

- Some of the participants expressed some initial nervousness about attending the sessions but by scheduling time in to do a check of the technology and an introduction, this helped people feel at ease
- After the sessions, some participants expressed that they enjoyed taking part in the research and were happy they had been listened to
- There was also an increase in personal confidence levels, as a result of taking part in the research, thanks to the 2- way conversational nature of the sessions, and the trust that had been built between the researcher and the participant
- Many would take part in research again

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*“I feel a lot more comfortable now and willing to participate in what and how this pandemic has affected us”*





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# Thank You



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