

RAPID RESEARCH IN COVID-19 PROGRAMME

Testing and trust: Public perceptions, expectations, and experiences of COVID-19 testing in Scotland

AIMS

COVID-19 testing is a cornerstone of long-term pandemic control. Public trust in testing is essential to the success of the government's testing strategy. This rapid qualitative study investigated public understandings, expectations, and experiences of COVID-19 testing in Lothian, Scotland. The study explored how people understand the purpose and value of tests, their motivations to undergo testing and follow government guidelines, and the ways in which perceptions and experiences of testing affect trust in government and health services. The study aimed to contribute to social understandings of medical testing, and to provide rapid feedback to the government and institutions involved in the administration of COVID-19 testing to help improve the efficacy of testing programmes.

KEY FINDINGS

- Participants are highly motivated to seek testing and 'do the right thing' regarding government guidelines. Undergoing testing is often seen as a duty to loved ones and society. In addition to its public health and medical functions, testing is valued for providing personal reassurance and enabling social intimacy and freedom of movement.
- The testing system depends on multiple relationships of trust: in government, technology, health workers, private contractors, other members of the public, family members, and oneself. Participants demonstrate high levels of trust in the Scottish government, the national health system, and testing technologies. They are less trusting of the UK government, private testing providers, online systems, and their own ability to collect a test sample correctly.
- People experience testing as a process rather than a discrete technical event. That process spans recognising symptoms and triage, accessing a test, taking a sample, and waiting for and interpreting results. At each stage, the testing process entails a significant and often unacknowledged 'diagnostic burden' of time, energy, and resources for the individual and their relatives/friends.

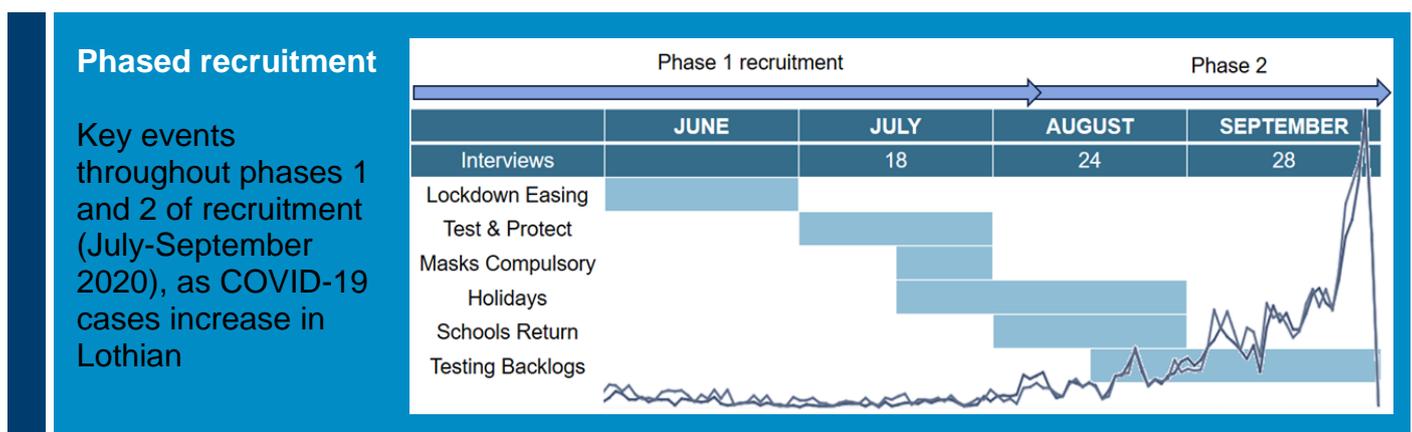
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- The diagnostic burden includes the weighing up of information from multiple sources, the interpretation of ambiguities in testing criteria and symptoms, the navigation of online bureaucratic systems, the organisation of testing logistics, the management of uncertainties around results, the matching of government guidelines to individual circumstances, and the handling of the repercussions of a positive or negative result. This burden is managed within social relationships and is often carried disproportionately by women.
- There is often a disconnect between the presentation of testing as straightforward in government documentation and personal experiences of testing as a social process in which multiple challenges are encountered. The gap between representation and experience can generate uncertainty, undermine trust in the government response, and weaken commitment to government guidelines.

WHAT DID THE STUDY INVOLVE?

From June to September 2020, we interviewed 70 members of the public in Lothian about their perceptions, expectations, and experiences of COVID-19 testing.

Recruitment: Participants were recruited through social media, mailing lists, and community groups. High-risk groups who were under-represented in the first recruitment stage (men, people identifying as Black, Asian, and Ethnic Minority (BAME), and people aged 65 and over) were targeted in the second recruitment stage. In total, we spoke to 70 adults aged 19–85, from a wide range of age groups, employment situations, and ethnic backgrounds. The sample included 49 women and 21 men. Eight participants identified as BAME. Six participants were employed as healthcare workers. Eight participants were over 65. 27 participants had direct experience of COVID-19 testing (defined as undergoing a test, arranging a test, or collecting a swab for another person).



Interviews: Participants registered through our project website (blogs.ed.ac.uk/testingandtrust), filled in a registration survey and informed consent form, and chose an interview slot online (Microsoft Teams) or by telephone. Interviews were semi-structured and followed a topic guide

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covering: personal experiences of COVID-19, testing experiences and meanings, understandings and expectations of tests, test results and behaviour, testing information, and opinions of the UK and Scottish government testing strategies. When participants had experiences of testing we focused on the 'testing process' in close detail. Semi-structured interviews took place against the backdrop of a continually evolving epidemiological situation, and iterative changes to the topic guide tracked unfolding events. Participants' concerns and the content of the interviews often reflected changes recently made to testing strategies and controversies that were prominent in the public media at the time of the interview (figure 1). Testing in Lothian increased steadily throughout the study, peaking toward the end of data collection in September, during which the majority of those with testing experiences (27) in our sample were interviewed.

Analysis: The whole research team was involved in analysis of the data, which was inductive and thematic. Transcripts were coded using the qualitative analysis software package NVivo (version 12). Coding followed the research framework outlined in the topic guide but was kept open to allow for the identifications of emerging themes in the data.

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

TESTING HAS A SOCIAL VALUE

We found that people placed significant value on testing and testing data for multiple reasons. Perhaps predictably, participants valued testing for keeping themselves and others around them safe. Many participants also used real-time population level data to guide their everyday decision making, such as when to leave the house and where to travel to (although people were not always sure how or where to access reliable data). We found that participants attributed social values to COVID-19 tests that went beyond the medical and public health functions of testing. For example, in a context of rapidly changing social norms, a negative test result provided people with reassurance that their behaviour towards others would not be deemed inappropriate (e.g. how to greet and interact with family, housemates, and strangers in a range of settings, whether it is acceptable to send a child to school or nursery with non-COVID illness symptoms, or to visit elderly relatives). Participants also valued the sense of social solidarity that participation in a nationwide testing programme provided them. A sense of civic duty and the desire to contribute to a collective pandemic response was a key motivating factor for many of those who sought testing and led some participants to persevere with the testing process in spite of the challenges they encountered.

TESTING IS A SOCIAL PROCESS

Our research shows that diagnosis is a more social, protracted, and distributed process than formal representations of the system suggest. Overemphasis on testing targets and the test as a single event can obscure people's experience of testing as a social process that is entangled with multiple relationships, and that can require significant effort and personal sacrifice to complete. Trust is a key element of those relationships: trust in the government to understand people's needs and make evidence-based decisions; trust in the healthcare system to deliver a high-quality service; trust that the testing technology is accurate; trust that others are getting tested when they experience symptoms and self-isolating; trust in oneself to interpret symptoms correctly, take a self-administered test correctly, and make the right decisions.

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The Test and Protect system relies for its success on members of the public undertaking a substantial burden of responsibility across the testing stages (triage; access; testing; results). While the vast majority of participants expressed their commitment to complying with guidelines, the lack of acknowledgement and support for their work has the potential to erode trust at multiple points in the system.

Testing as a social process

The testing experience is shaped by interconnections between the testing process, relationships of trust and the social, economic and emotional burden of diagnostic work. This burden is often disproportionately managed by women through social relationships within and between households.


Triage: The testing process begins well before someone books a test

Perceived levels of exposure, workplace conditions, anxiety over health status, local case data, friends' stories and media accounts of asymptomatic spreaders all affected a person's trust in testing even before they experienced any symptoms. Once symptoms developed, many people struggled to match their experience to formal criteria. 'Continuous cough' and 'fever', for example, were experienced as ambiguous. In some cases, difficulties encountered in accessing a test and/or self-isolating while waiting for results led people to interpret the guidelines liberally (e.g. waiting to see if a temperature dropped before self-isolating and booking a test). In some cases, the realisation that others must be making similar decisions eroded trust in the efficacy of Test and Protect.

Access: Government representations of testing as easily accessible conflicted with people's experiences of practical challenges

Individuals navigating the government's online testing platform encountered a variety of practical issues: booking errors, a lack of slots in their area, and/or difficulties in negotiating transport in a COVID-safe way. In some cases, despite efforts to comply with guidance and high motivation to 'do the right thing', participants claimed it was not always easy due to the locations of testing centres. Many felt that the time they had taken off work—to organise a test for themselves or their child, to drive to a testing centre, and to wait in self-isolation for the results—had not been sufficiently acknowledged.

Test: People are often unprepared for the physical experience of testing

Swabbing correctly is a complex task. In cases of self-testing, interviewees felt burdened by the expectations placed upon them and questioned the lack of support from trained medical staff on site. Formal guidelines present the self-test as straightforward, but participants did not always find the instructions easy to follow and often worried they had collected the sample incorrectly. Swabbing younger children and children with special needs in particular represents an emotional and physical challenge for which many people felt unprepared. Negative testing experiences were often linked to a distrust of privately contracted testing services.

Results: People don't always take test results at face value

A negative result can create a sense of reassurance and safety, and enable social obligations and interactions at home and at work to resume. But test results are not always taken at face value. Receiving a test result that conflicts with initial diagnostic suspicions can raise doubts about the quality and accuracy of tests, healthcare staff, or sampling techniques. Participants indicated a willingness to follow government guidelines on test results but, in practice, when specific guidelines (e.g. self-isolation) conflict with social, practical, and economic needs, some participants interpreted them flexibly without necessarily seeing this as breaking the rules.

WHAT IMPACT COULD THE FINDINGS HAVE?

Our research shows that there is public demand for testing, and that people are willing to go to considerable efforts to make the testing system work, despite the inconveniences and personal sacrifices involved. Nonetheless, more can be done to improve the testing process and to recognise the burden of effort and resources it places on individuals:

- Improve the visibility and accessibility of up-to-date testing and case data at national and local levels via trusted (NHS or Scottish Government) sources. Provide explanations of data reporting.
- Improve public guidance to address ambiguities in the testing criteria. For instance, provide examples of scenario-based decision making to help people decide whether or not to book a test, and provide clarity on what will be expected of people during the testing process.
- Improve transparency of booking system algorithms and decision making.
- Address public scepticism about private testing contractors through greater transparency around the awarding of contracts and/or by emphasising links to the NHS.
- Increase the number of local walk-in testing centres in the community setting.
- Provide pre-test counselling and training, especially in scenarios where people are expected to collect a swab sample from themselves or others. Create short videos (with accessible and child-friendly content), and/or tailored advice for testing children and people with disabilities. Procure 'accessible' tests with less invasive sampling techniques for those who need them.
- Use language that conveys appreciation for the effort that testing requires, and acknowledges the challenges people may face in accessing/undergoing/acting upon testing/complying with guidelines. Emphasise the contributions of individual actions to a societal response. Remove barriers to self-isolation through improved economic and practical support.

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HOW WILL THE OUTCOMES BE DISSEMINATED?

Findings have been disseminated to academic, policy, and public audiences via a variety of media, including two academic workshops, a live stakeholder webinar and a Europe-wide public seminar. Research briefs and findings have been published on the project website. Two commentaries based on the research have been published in The Scotsman newspaper. Two articles are under development for submission to international peer-reviewed journals in early 2021.

Future research: Funding from the University of Edinburgh enabled us to take this research forward in relation to the use of lateral flow devices for testing asymptomatic students (Dec 2020) and the rollout of a University of Edinburgh developed testing platform for routine testing on campus (Mar 2021). Alice Street is Co-I on a UKRI proposal to research social experiences of routine COVID-19 testing on university campuses.

RESEARCH TEAM & CONTACT

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ADDITIONAL INFORMATION

This RARC-19 funded project received £30,000 and was completed on October 31st 2020.