



Every Story Matters Record In Brief: Test, Trace and Isolate System

The UK Covid-19 Inquiry is an independent public inquiry examining the response to, and impact of, the Covid-19 pandemic to learn lessons for the future.

The work of the Inquiry is divided into separate investigations, known as modules. Each module is focused on a different topic, with its own public hearings where the Chair hears evidence. Following the hearings, a module report is published, which contains findings from the evidence collected across the module and the Chair's recommendations for the future.

How Every Story Matters fits into the Inquiry's work

This summary relates to the Every Story Matters record for Module 7, which examines the Test, Trace and Isolate System used during the Covid-19 pandemic. Future Every Story Matters records will focus on different aspects of life during the pandemic such as social care, children and young people and financial support.

The Every Story Matters record for Test, Trace and Isolate System brings together people's experiences shared with us:

- online at everystorymatters.co.uk;
- in person at drop-in events in towns and cities across the UK; and
- through targeted research with specific groups of people.

Each story is anonymised, analysed and organised into module-specific Every Story Matters records. These records are entered into evidence for the relevant module.

The record makes reference to significant harm and some of the stories and themes included in this record may trigger upsetting memories and feelings. It may be helpful to take a break if reading the record is upsetting. A list of supportive services is provided on the [UK Covid-19 Inquiry website](#).

Introduction

Every Story Matters is neither a survey nor a comparative exercise. It cannot be representative of the entire experience of the UK, and nor was it designed to be. Its value lies in hearing a range of experiences, in capturing the themes that have been shared with us, quoting people's stories in their own words and, crucially, in ensuring people's experiences are part of the Inquiry's public record. This summary sets out some of the experiences shared by people of Covid-19 testing, contact tracing and self-isolation during the pandemic. For this record, self-isolation refers to someone isolating after receiving a positive Covid-19 test result or a notification about a close contact having Covid-19 through the contact tracing system. The record does not include experiences of being isolated or feelings of isolation as a result of a national lockdown.

Understanding and awareness of Test, Trace and Isolate

Some of the areas people told us about were:

- Many contributors felt the guidelines around testing were initially clear, but confusion grew over time due to changing rules and lack of awareness about contact tracing.
- People were left confused by changes to official government guidance about when to test and self-isolate. Uncertainty about the rules in place at any one time meant that some people decided to do what they thought was appropriate regardless of whether or not it aligned with the rules.
- Some contributors described how their awareness and confidence in knowing when to test grew over time as a result of having symptoms and experiencing the virus or hearing about the experiences of others with Covid-19. However some contributors also told us that they were confused about knowing the difference between symptoms of Covid-19 and other similar illnesses, such as colds and the flu.
- Contributors described difficulties accessing or keeping up with information about testing. This included people who did not use the internet and people whose first language was not English.

- Some contributors explained how they had found contact tracing information unclear, that it was hard to understand the purpose of it and to follow the guidance correctly.
- Few people seemed aware of the financial and practical support that was available when self-isolating.

What helped or encouraged people to participate in testing, contact tracing and self-isolation?

Some of the areas people told us about were:

- **Protecting people they cared about and others:** Many people were motivated by their sense of moral duty to protect their loved ones, their communities and those who were vulnerable.
- **Requirements:** Some people were required to test (regardless of symptoms) before coming into work and into contact with other people. Some described this as part of their 'duty of care' to protect others.
- **Access to support:** Some felt the practical support they received – from family and friends, local organisations and community groups – enabled them to engage in testing, contact tracing and to self-isolate.
- **Increasing freedom:** As time went by contributors said their desire to attend schools, colleges and universities, to travel and to mix and socialise with others became a reason to test.
- **Reducing worry:** Contributors expressed that they were scared of catching the virus, becoming seriously ill, or passing it on, which led them to get tested, participate in contact tracing, and self-isolate.
- **Access and convenience:** Contributors told us that it was easy to get tested when testing centres were easily accessible and there was good availability of appointments. When Lateral Flow Tests (LFTs) were made universally available to everyone in April 2021, many welcomed the ease and convenience of free kits to test at home. Being able to test at home was also reassuring for people concerned about the risk of infection at or on the way to test centres.

What were the barriers to people participating in testing, contact tracing and self-isolation?

Some of the areas people told us about were:

- **Trust:** People became increasingly sceptical and distrustful of testing and contact tracing because they thought they were inaccurate or ineffective. There was a shift in people's attitude with regards to following guidance once news broke about politicians and officials breaking rules.

- **Perception of risk:** Personal perceptions of risk influenced people's participation in testing, contact tracing, and self-isolation, and this shifted throughout the pandemic.
- **Access:** Complicated test booking systems or a shortage of available LFT tests made it challenging to access tests.
- **Difficulty of use:** We also heard that people experienced barriers using LFTs correctly, interpreting results and switching between the different variations of test kits.
- **Discomfort and distress:** People shared their experiences of discomfort and distress from testing, as well as the challenges of self-isolation, which included a sense of lost personal freedom.
- **Living arrangements:** For some, it was not always practical to follow the guidance – particularly about self-isolation - for example, if they lived in smaller or cramped homes.
- **Lack of support:** Where people did not have access to support, they struggled to engage in testing, contact tracing and self-isolation. For example, when contributors told us they did not have friends and family close by, they sometimes struggled with self-isolation and did not always know where to seek support during these times.

Fixed Penalty Notices (FPNs)

Some of the areas people told us about were:

- Contributors had mixed opinions about the effectiveness of FPNs as a deterrent to breaking self-isolation rules. Some felt that the threat of fines encouraged adherence, while others believed harsher penalties were necessary for greater effectiveness.
- A number of contributors viewed the fines as ineffective.
- For contributors who had immigrated to the UK, there was anxiety about the broader implications of receiving a fine, which compounded their caution in adhering to the rules.

What were the experiences of specific groups of the Test, Trace and Isolate System?

Some of the areas people told us about were:

Parents:

- Described testing their children as challenging.

- Said they found it particularly difficult when they needed to carry out tests on children with autism, ADHD and other complex needs due to sensory difficulties.
- Shared concerns about the appropriateness of testing very young children due to the distress and discomfort that it caused.
- Told us that they found self isolation difficult with young children.

Those who helped older people:

- Told us that older people with physical conditions such as arthritis or tremors often needed others to help them test. Some contributors felt tests could have been more inclusive for people with limited manual dexterity to allow them to use tests independently.
- Shared that testing older people with neuropsychological conditions, such as dementia, found it challenging to do so due to a lack of understanding among those being tested about what testing was and why it was needed.

Deaf¹ and disabled people:

- Told us test kit instructions were difficult to understand and use; and that having instructions in other formats would have made them easier to use.
- Had mixed experiences on the accessibility of testing centres, including some testing centres that were not accessible to wheelchair users; while others shared that staff at their local test centre were well prepared for providing additional support such as visual instructions for d/Deaf people.
- Some spoke of how they experienced communication barriers at test centres, and said the staff working there did not appear equipped to support people with a variety of needs. Others shared how staff were well prepared to support those with access needs such as having additional easy to read printed materials.
- Were especially impacted by the closure or reduced services of community organisations. For example, some contributors had no one to help them organise online food deliveries from supermarkets making it difficult to access the essentials while self-isolating.

¹ The Inquiry recognises the wider inclusive term of “d/Deaf” although the people spoken to as part of the record identified as “Deaf”.

People who have literacy difficulties and/or digital exclusion:

- Sometimes had difficulty understanding the written instructions in test kits and would require support from friends or family to use tests.
- Sometimes felt that their needs were not met by the test booking systems.
- Reported feeling confused about how to access and use tracing apps, which made them feel anxious.

Bereaved people:

- Shared how self-isolation guidelines prompted them to reflect on their decisions to visit a dying loved one in hospital.
- Told us that the emotional toll was profound if they were unable to mourn or grieve with others due to self-isolation.

Victims and survivors of domestic abuse:

- Told us how they felt pressured by their partner to follow or not follow self-isolation guidelines in accordance with the stance adopted by their partner.

Suggestions for improvements for the future

When reflecting on how testing, contact tracing and self-isolation could be improved in a future pandemic, contributors noted the following might help:

- Greater consistency and clarity in government policies and messaging across the devolved nations.
- Better use of community leaders in disseminating information to communities.
- Accessible information available in different languages and formats, including more diagrams in test pack leaflets, and links to online videos showing the steps using British Sign Language (BSL).
- More public education on the need for testing, contact tracing and self-isolation.
- Improved access to mental health support for people during periods of self-isolation.
- Better access to financial and practical support for people during periods of self-isolation.
- Alternative options for digitally excluded people and those living in remote or rural areas.

To find out more or to download a copy of the full record or other accessible formats, visit: <https://covid19.public-inquiry.uk/every-story-matters/records/>